

THE *JACKSON* FAMILY SURVEY: FINAL REPORT ON FOUR YEARS OF RESEARCH

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BY

JRB ASSOCIATES

P. O. Box 1387
Corrales, NM 87048
505 898-6015

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***State of New Mexico
Developmental Disabilities Planning Council***

Christine Parkhurst, Chairperson

Chris Isengard, Executive Director

Project Monitor: Kathy Dickerson, Planner

JRB Associates Project Team

Jackson Longitudinal Study Field Research Associates

Cathleen Cain

David Pieters

Nancy Pieters

JLS and Family Survey Research Analyst

John G. Bretting, Ph.D. **Project**

Management and Report Preparation

John R. Brown

Foreword

In 1992, the New Mexico Developmental Disabilities Planning Council (DDPC) commissioned the *Jackson* Longitudinal Study to assess "ongoing consumer satisfaction" among members of the developmentally disabled population who were discharged from state facilities, specifically the Los Lunas Hospital and Training School and the Fort Stanton Hospital, and moving into new living arrangements in the community. The *Jackson* study also sought to continue to discover the changes in the lives of these individuals and their families as they made this major life transition. The DDPC contracted with JRB Associates of Corrales, New Mexico to conduct the research.

This process of "deinstitutionalization" resulted from a Federal District Court ruling in the class action lawsuit, *Jackson vs. Fort Stanton*. The suit was filed in 1987 by the New Mexico Protection and Advocacy System on behalf of a Los Lunas patient and others in a similar situation at Los Lunas and Fort Stanton, New Mexico's two large public intermediate care facilities for the mentally retarded. Judge James A. Parker, in his ruling, found that the state had failed to provide acceptable conditions at both hospitals, and that the state didn't provide the same opportunities for people with severe disabilities to live in the community as it provides for less disabled people.

Judge Parker's 1990 order required the State of New Mexico to (1) develop a plan to correct the constitutional deficiencies found at the hospitals and (2) develop transfer plans to place those individuals who would benefit from care in community settings. It should be noted that in 1997, the state of New Mexico closed its last large public institutional facility housing people with developmental disabilities.

This past year was the final year of research for both the *Jackson* Longitudinal Study and the *Jackson* Family Survey.

The *Jackson* Longitudinal Study

The following is a summary of the overall conclusions of the *Jackson* Longitudinal Study:

- More *Jackson* members like living in the community-based residential environments more than liked living in the institutional settings.
- More individuals would prefer to stay at their current residence rather than to move, when posed with the alternatives. Of those who would rather move, most cited wanting to be with their family. Expressing such a preference, however, did not mean that

residents were dissatisfied with their current home, which the researchers regard as an important measurement of consumer satisfaction.

- Field researchers associated with the Study have observed, over time, the absence of barriers to residents' mobility, in addition to improved quality of the physical environment in the community homes.
- Physical access to the community for *Jackson* class members has improved dramatically, which corresponds to the researchers' finding that more individuals either have the adaptive equipment they need or have less need for such equipment in the community environment.
- The majority of staff in both institutions and community homes were found to speak and act respectfully in their relationships with *Jackson* class members, and most staff, regardless of setting, were deemed to be "acceptably knowledgeable" about the health needs of the *Jackson* clients. However, community staffs level of knowledge has decreased over time, likely due to the high rate of turnover among residential staff.
- Choice of day program ("school, training or work") is just as limited in the community setting as was the case in the institutions. There is evidence that a growing minority of residents are dissatisfied that, for the most part, that "someone else" selected their programs.

In the third year report, the researchers hypothesized there was a "quiet revolution of rising expectations" that might explain some contradictions in the *Jackson* data. The hypothesis was posed to explain the finding that while residents were becoming increasingly empowered in the community, some also had expressed increased dissatisfaction with some aspect of their lives. The researchers note in the final report that although this hypothesis was not strongly supported by the final year data, they were reluctant to discard the idea that as residents in the community gained opportunities to make choices in some areas of their lives, they were more likely to express dissatisfaction about areas in which they didn't have these choices.

The *Jackson* Family Survey

In 1993, the DDPC decided to expand the scope of work of the *Jackson* study to include information gathered from parents or from family members who were acting as guardians of *Jackson* clients. This information is compiled in the *Jackson* Family Survey.

The following is a summary of key findings of the *Jackson* Family Survey:

- » Survey respondents report that opportunities for *Jackson* Class members have improved. One exception, however, concerns the matter of recreational activities, which respondents noted that movers are far less likely to participate in physical activities which require planning and more likely to watch television than was the case in the institutional setting.
- Respondents believe that access to special therapies, recreational activities, medical services and transportation has improved since their relatives or wards moved into the community settings.
- The highest mean score given by respondents had to do with the movers' well-being. Overall rankings of welfare and well-being, level of happiness, quality of medical services and the health of relatives have improved in the community environment. The researchers note this global finding is a strong indicator of parental and guardian satisfaction with the outcome of the transition from state institutions to the new homes in the community.
- The researchers conclude the movement of the *Jackson* class members to the community has not had a major impact on the lives of the survey respondents and their families, indicating the adaptability of parents, guardians, and their families to the new living arrangements. They suggest this means that while families are inherently concerned with their *Jackson* class member, they are able to continue in their day-to-day routines just as other families do when a member relocates or changes residences.
- Mean score measures of *Jackson* class family members indicate parents and guardians' concern not only about the general welfare and well-being of their daughter, son, or ward, but also about who is going to care for their relatives when they are no longer capable of doing so.
- The researchers report an overall perception of optimism and approval, despite reports of instances in which survey respondents report dissatisfaction with specific situations. Family members and guardians indicate general satisfaction regarding the improvements in the quality of life and living environment of their son, daughter, or ward.

While both the *Jackson* Longitudinal Study and the *Jackson* Family Survey indicate high levels of satisfaction, the perceptions of satisfaction are not universal. This fact suggests the importance of continuous monitoring of the various quality of life issues related to the transfer from the institutional to the community settings to ensure that the needs of all involved are met.

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CHAPTER 1

INTRODUCTION

Background

This section describes the relationship between the Family Survey and the Jackson Longitudinal Study.

This research is intended to measure the effects of implementing court-ordered transition plans on movers and their families.

The Jackson Longitudinal Study was designed to measure "Quality of Life" from the movers' point of view.

This is the final report on the *Jackson* Family Survey. The Family Survey grew out of, but is separate from, the *Jackson* Longitudinal Study (JLS). The JLS is a five-year project, which is also in its final year. The JLS was commissioned by the New Mexico Developmental Disabilities Planning Council (DDPC). It assesses "ongoing consumer satisfaction" among people with developmental disabilities who have been discharged from state-operated congregate housing and care facilities (Fort Stanton Hospital and Training School and Los Lunas Hospital and Training School), and who are moving into new community living arrangements.

In New Mexico, the transition process came about as a result of a federal district court 1990 decision in a class action lawsuit known as *Jackson v. Fort Stanton*. The *Jackson* case ruling affirmed the right of people with severe and multiple disabilities to live in "least restrictive" community settings. It required the State to develop transfer plans to place in community settings those individuals who were found not to require institutional care.

The primary evaluation study, the JLS, was intended to track over five years the progress of the "deinstitutionalization" or community placement strategy. In designing and implementing that study, JRB Associates understood "ongoing consumer satisfaction" to mean the satisfaction of the *Jackson* Class members themselves (rather than those of their families or of professionals in the field).¹ Our research to the extent possible focused on assessing dimensions of the quality of the *Jackson* Class members' lives in terms of *their* experience, and from their perspectives. The principal focus during Year 1 was to establish baseline data about their level of satisfaction while they were still residents of the institutions.

¹ The concept of "Quality of Life" has been discussed in the disabilities literature for several years, but agreed-on criteria for defining it and for measuring the elements it may include have been lacking. Using criteria developed by the DDPC's Quality Assurance Task Force in 1992 and drawing on research on deinstitutionalization done in other states, the JLS design identified several components of QoL and developed interview questions and observation criteria to measure them. The approach we have taken and the dimensions and components we chose appear to be supported by a recent review of the status of research on this issue: *see* Hughes, C. et al. (1995, May). "Quality of Life in Applied Research: A Review and analysis of Empirical Measures." *AJMR* 99:623-641.

To do this, JRB Associates' researchers held structured interview and observation visits with a representative sample of the *Jackson* population at Fort Stanton and Los Lunas Hospitals. Then, using the same instruments, which are being administered yearly for five years to a larger number of *Jackson* clients at their homes in the community, JRB Associates began the process of measuring how their quality of life has changed since their move.

Jackson Longitudinal Study reports may have implications for policy and community based programs.

In March 1997, JRB Associates completed its fourth year report on our findings from the JLS.² That report was based on analysis of 368 interview and observation visits held over a four-year period with 98 *Jackson* Class members. These annual reports are designed to provide feedback to all stakeholders, including the DDPC, the Department of Health, clients and their relatives, providers and others. JRB Associates' sole purpose has been to collect and analyze the field data and report our findings in an objective manner. We have not sought to make policy recommendations or to advocate changes in services provided in the community settings. However, we realized from the outset that our work would be likely to affect policy considerations as it progressed.

Obtaining Parents' Perceptions and Input

Because the JLS doesn't solicit their views, the DDPC asked for an additional survey of parents' and guardians' attitudes.

As we presented progress reports to the DDPC, JRB Associates received feedback from some members to the effect that the study design failed to include the views of parents. For the reasons just discussed, this had not been in our original scope of work. However, before the second year of the JLS was funded the Council (DDPC) decided that it would indeed be useful to gather information from parents or family members who were acting as guardians of *Jackson* clients. JRB Associates was given additional resources to begin undertaking a "Parent-Guardian Survey" (which was later re-named the "Family Survey") beginning in 1994, the second year of the JLS. The Family Survey, like the JLS, is designed to be a "longitudinal" study, and is planned to be carried out each year for the duration of the *Jackson* Longitudinal Study.

Purpose and General Approach

The Council wanted the Family Survey to find out how the Jackson process affects family members.

In authorizing the Family Survey, the Council had two purposes in mind. The first purpose was to learn parents' and family member guardians' opinions about how moving into the community has affected their son or daughter or relative. The second — and equally important — was to learn

JRB Associates (1997, March). "The *Jackson* Longitudinal Study: Findings of Four Years of Research." Corrales, NM: [Santa Fe, NM: New Mexico Developmental Disabilities Planning Council]. The report is available from the DDPC.

about the effects the *Jackson* process is having on other members of the family.

This survey uses a mailed questionnaire to gather information from parents or family members who are acting as guardians of *Jackson* class movers. The questions have been designed to assess their *perceptions* of changes in the quality of life of their family member who belongs to the *Jackson* class. Additionally, it asks the parents and family guardians about aspects of their own and other family members' level of satisfaction and comfort with the transition process and its outcomes to date.

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intentionally blank.)*

CHAPTER 2

DEVELOPMENT AND IMPLEMENTATION OF THE FAMILY SURVEY

This chapter discusses the way the Family Survey was designed and how it has been implemented. It deals with some of the issues presented in the choice of questions, the selection of the survey samples, and difficulties we have encountered in obtaining an adequate response rate.

The Focus Group

We brought together a representative "focus group" of parents to help us design the survey questionnaire

Before designing the survey instrument for the first Family Survey in 1994, JRB Associates conducted a focus group of parents and family member guardians. Focus group participants were carefully selected to obtain a balance among parents who had originally supported the aims of the *Jackson* lawsuit and those who had initially opposed it. We also strove to achieve ethnic balance and to represent both guardians whose son, daughter or ward had already moved to the community and those who were still waiting for the transition to occur. The group was convened to discuss their opinions and concerns about the transition of their sons or daughters from an institutional setting to a community-based living arrangement. The important ideas and opinions shared by the participants in the focus group had a direct influence on the design of the questionnaire.

Three primary issue areas emerged during the focus group discussion. They were:

- some parents' disillusionment with the transition process and sense of lack of voice or power to affect the process;
- specific concerns regarding the competence or stability of their family members' residential providers; and
- a perception that the responsibilities of the parents were greatly increased after the *Jackson* Class member relocated to a community living arrangement.

These areas of concern became the basis for some specific questions we asked in the survey, and for our analysis of responses, particularly to the open-ended question at the end. (**Appendix A** is a copy of the survey instrument used in Years 3 and 4. The questionnaire was also translated into Spanish.)

The Population Surveyed

One result of our focus group discussion was a decision to administer the survey only to parents or family member guardians of *Jackson* class members **who had already moved into the community**. The focus group results suggested that prior to their son or daughter's move some

The guardians' experience with their Jackson relatives' lives in the community was important.

Only family member guardians whose relatives have already moved to the community receive the survey.

parents were likely to have exaggerated expectations (fears or hopes) about what might happen during and as a result of the move. We determined that it would be more helpful to examine the responses of those parents/guardians who had first-hand experience with the transition process, than to focus on the pre-move apprehensions of those who had not yet experienced any results of their son's, daughter's or ward's actual move.

Initially, JRB Associates had agreed to administer the survey to a sample of 50 parent or family-member guardians. "Corporate guardians" (primarily The ARC of New Mexico) were not included for obvious reasons. As of April 1, 1994, 64 *Jackson* Class members with parent or family member guardians had moved from the institutions and were living in communities within New Mexico. As a result, we decided that it would be just as easy to survey *all* of the parents/guardians of these individuals. Consequently, in the first year we mailed questionnaires to 62 family member guardians. (Two sets of siblings among *Jackson* movers account for the difference.) Using the same criteria, In year two, we mailed surveys to 97 guardian addresses, and in year three to 98. After culling erroneous addresses from previous years' undeliverable letters and updating others, we sent 94 questionnaires this year.

The Survey Design

The Family Survey, mailed to parents and guardians, is short and simple to get the best response rate possible.

The Family Survey is a longitudinal study, asking mostly the same questions each year to assess changes over time.

Our plan for the Family Survey was for a separate longitudinal study of parent/guardian opinions, gathered through a mail survey. We proposed to "piggy-back" this survey on the JLS, using the same address database we had employed to seek parents' or guardians' permission for their wards to participate in the JLS. Because we had already made efforts to update this information, it seemed likely that we could reach most parents or other family member guardians through such a mailing. We also knew we should keep the survey short and simple in order to get an adequate response rate. Earlier research tracking deinstitutionalization in other states provided a framework for many of the questions.

Like the JLS, the Family Survey was planned as a longitudinal study. Using instruments that include many of the same questions each year, we are tracking parents' and guardians' perceptions of changes in their *Jackson* Class relative's and their own and other family members' quality of life over a four-year period (the planned time remaining for the JLS). The first year Family Survey provided baseline data about these issues. Some questions were drawn from similar surveys in other states. Others, including those about the *Jackson* transition process, directly reflected the concerns of our focus group members. In the second year we asked most of the same questions in order to examine evolution in the pattern of responses. We altered the wording of a couple of questions to reflect the fact that many of the movers had completed the official "transition" stage, and were undergoing a period of adjustment to community living. We also added a four-part question (Number 10) about problems related to community living. Responses to these questions are not comparable to year one, but are analyzed for the later years.

Implementing the Survey

The Year 1 survey was mailed to 62 parents or guardians, and we received 32 responses, about 52 percent.

In Year 2, surveys mailed to 88 parents or family member guardians yielded 36 responses, about 41 percent.

Because of the low response rate, we were worried about possible sample bias.

To correct for possible bias we performed additional analysis in Year 2, using responses from a "panel" of 19 who had responded in both years.

In years 3 and 4, we decided not to use the panel in light of a better response rate - nearly 50 percent this year - and instead to focus on longitudinal trends.

On April 29, 1994, the Year 1 Family Survey was mailed to 62 parents or other family guardians of *Jackson* Class members who were living in the community as of April 1, together with a stamped return envelope for responses. Returns for wrong addresses were followed up by contacting the institution from which the client had moved to obtain correct address information. Follow-up letters were sent and calls were made to non-respondents during a two-week period in mid-May, and the survey was re-mailed to those who agreed to participate but had misplaced the original questionnaire. By June 15, our cutoff date, we had received 32 completed survey questionnaires. This response rate (51.6%) was less than we had expected or hoped for but is generally considered adequate for analysis and reporting. Our analysis and the "Family Survey First Year Report" were completed in September 1994.

In the second year we followed the same procedures, mailing the survey to 97 people who had been identified as parents or family member guardians. (A few turned out to be corporate guardians, as we found out in follow-up phone calls.) When we learned from postal returns that we had the wrong address or a change in guardian had occurred, we attempted to follow up. We ended eventually with 36 responses out of 88 actual parents or family member guardians who received the questionnaire. This constitutes a 40.9% response rate, which is disappointing, but again adequate for analysis, within limits dictated by the small size and self-selection of the sample. (Sample size is in this instance less important than the fact that we don't know why 60% of those we were able to reach by mail chose not to participate. It is plausible to suspect that their attitudes toward the *Jackson* transition process and its outcomes to date may have influenced their decisions. Thus, a low response rate introduces a source of bias into our data.)

To improve comparability in our analysis, we identified 19 parents or guardians who had responded to both the first and second year surveys. (This subset of our samples is called the "panel" in the discussion below.) For certain key questions we examined how changes in the panel's responses compared to differences between the entire first and second year samples.

In Year 3, the response rate had improved significantly, and longitudinal data for three years began to yield interesting trends. We were able to mail surveys to 90 correct addresses and had received 42 responses, or 46.7%, by our deadline. We decided *not* to use the panel in our analysis for year 3, because the sample of families that responded to the survey all three years was too small to be statistically valid. (Of the total N of 42, twelve respondents were new in year 3, and three more had responded in Year 1 but not Year 2. Twenty-seven had responded in Year 2 only.) Moreover, the improving response rate gave us greater confidence in interpreting the data than we had in year 2.

In Year 4, we received 43 responses out of 88 successfully delivered questionnaires, including nine guardians who had not responded in the past and five others who did not respond in Year 3 but had done so at least once earlier. This rate, just under 49%, was the best response received in any year since we began the Family Survey. (One additional response was received after we had analyzed the data, and so was not included, but would have brought the response rate to 50%.) Our confidence in the validity of the longitudinal data is improved on account of the higher response rates in the last two years of the study

In all, 70 different parents or guardians (or families) responded to our survey during the four-year period. Of these, 30 responded once, 12 responded twice, 13 responded 3 times, and 15 responded in all four years. .

CHAPTER 3 DEMOGRAPHIC PROFILE OF THE SURVEY SAMPLE

This chapter briefly discusses some relevant characteristics of the *Jackson* Class members, related to the length of time they (those whose parents or guardians responded to our survey) had lived in an institutional environment, and the implications this might have for the Family Survey. A more exhaustive demographic profile of the *Jackson* Class members is contained in the various reports of "The *Jackson* Longitudinal Study." Chapter 4 consists of analysis of the data for each item of the questionnaire. Overall findings and conclusions based on the analysis are reported in Chapter 5.

History of Institutional Stays

We reviewed demographic data about the movers whose parents and guardians responded to the Family Survey.

Table 3.1 on the next page provides summary statistics about *Jackson* Class individuals whose parents or family member guardians responded to the Family Survey in Year 4. These benchmark data track the history of the individuals' institutionalization. The data may be utilized as control variables, to test hypotheses and examine relationships relevant to the parents' or guardians' perceptions and opinions. Basic information includes the age at which the respondent's son, daughter, or ward entered the institution; the total number of years he or she lived in an institutional setting; the age he or she moved into a community living arrangement; and her or his current age.

Table 3.1 Ages and Institutional Stays of Survey Sample Wards (Year 4)

Survey code	Age admitted to an institution	Moved to the community	Years in an institution	Age now	Years since community placement
5	12	Jun-93	25	41	4.0
9	10	Dec-92	14	28	4.5
19	13	Jun-94	21	37	3.0
20	2	Nov-93	26	32	3.6
25	15	Feb-95	11	28	2.4
32	41	Dec-93	28	72	3.5
36	24	Nov-93	3	31	3.6
38	6	Aug-93	21	31	3.9
39	9	Jan-94	30	43	3.5
40	13	Jun-94	31	47	3.0
41	6	Mar-94	23	32	3.3
42	43	Jun-93	8	55	4.0
48	13	Jan-94	31	47	3.5
52	19	Dec-93	31	54	3.5
59	29	Sep-93	6	39	3.8
61	28	Jan-94	7	38	3.4
64	8	Aug-93	26	38	3.9
65	14	May-94	8	25	3.1
69	10	Jul-93	30	44	3.9
70	13	Dec-93	9	26	3.5
74	9	Jul-93	24	37	3.9
75	20	May-93	6	31	4.1
77	22	Jul-93	13	38	4.0
80	26	Feb-94	4	33	3.4
82	0	Mar-93	51	55	4.3
85	29	Dec-93	13	46	3.5
87	30	Nov-93	7	40	3.6
89	19	Sep-93	34	57	3.8
93	12	Jul-94	20	35	3.0
94	11	Jul-93	30	45	4.0
97	43	Mar-93	3	51	4.3
101	21	Apr-93	8	33	4.2
102	46	Apr-94	6	55	3.2
108	17	Jun-93	17	38	4.0
109	12	Dec-93	15	31	3.5
114	22	Oct-95	9	33	1.7
115	26	Jul-95	14	42	1.9
116	12	Aug-94	18	33	2.9
120	25	May-94	14	42	3.1
140	5	Jan-94	28	36	3.5
143	7	Jan-94	26	36	3.5
148	12	Apr-93	28	44	4.2
150	20	May-94	8	31	3.1
Average for Year 4 sample	18		18	40	3.5
Compare to Year 1:	13		22	40	0.6
Compare to Year 2:	17		22	37	1.8
Compare to Year 3:	14		22	39	2.5

The mover data may help us understand and explain the Family Survey responses.

As we have noted in earlier reports, these demographic data provide important context for our survey findings. Note first that the sons or daughters or wards of parents and guardians who responded to the Family Survey had lived in state institutions for a significant length of time. The average length of stay in an institution (for this group) is 18 years. It was 22 years for the earlier survey samples. The range is from three to 39 years. Twenty of the 43 sons, daughters or wards of our Year 4 sample (approximately 47 percent) had lived in an institution for at least 20 years.

Changes in parent-guardian responses in later years may reflect lessening anxiety about their family member's move as Jackson clients live longer in the community.

Did familiarity with the institutional setting and institutional levels of care for their sons or daughters or wards influence the parents' and guardians' opinions? In Year 1 we speculated that they might be skeptical about the community-based living arrangement, especially if they had been satisfied with the provision of service by the institution in the past. On the other hand, if they had not been satisfied with the provision of care by the state institution their responses might reflect a pre-bias in favor of the community-based living environment. The first year data did not provide conclusive findings. However, by the second year, our evidence began to suggest that parents and guardians may have become less anxious over time about the lives of their wards in the community. As **Table 3.1** shows, the average length of time the *Jackson* Class relatives of our sample had lived in the community at the time of our Year 4 survey had increased to 3.5 years from 0.6 years in Year 1, 1.8 years in Year 2 and 2.5 in Year 3. The data on this question analyzed in Chapter 4 indicate that the trend continues.

Calculations based on **Table 3.1** also show that the median age of the respondents' *Jackson* Class relatives, at the time they moved into a community living arrangement, was 34 years. Their ages at the time of placement ranged from 13 to 68 years. Two movers were teenagers. Twenty-nine percent (N=12) were in their twenties at the time of their move; 29 percent (N=12) of the movers were in their thirties; 14 percent (N=6) were in their forties, 19 percent (N=8) in their fifties, and one was over sixty.

The parents' ages and the length of time their relative had lived in an institution may have made them anxious about any change.

What might this mean? Many of these parents and other family member guardians are well into the second half of their lives. They have worked for many years; some have retired and others are not far from retirement age. It is reasonable to believe that parents in such a situation had likely long ago come to terms with the appropriateness of their decision to place their child in an institution, and had come to depend upon the institution to care for their son or daughter.

Table 3.2

Relationship of Respondents to their *Jackson* Class Member

Survey	Mother	Father	Other
Year 1	20	4	8
Year 2	21	5	10
Year 3	27	5	10
Year 4	27	8	8

"As the 'unknown' becomes the 'normal'... we might expect such worries to subside." This has not proven to be true.

In the Year 1 Family Survey, we suggested that the *Jackson* decision and the prospect of community placement might be expected to have disturbing implications for such parents, especially in light of their own ages. They might well be concerned about effects of the placement on their own welfare and wellbeing. They might feel more responsible and yet experience "helplessness" with regard to their ability to assist in the care of their now adult son or daughter. They might worry about whether this change portends abdication of all state responsibility in the future, and about what may happen to their son or daughter when they are no longer able to monitor their care. As the "unknown" becomes the "normal" in later years, we might expect such worries to subside. In fact, though in general this may be true, for a significant minority of respondents the level of worry has actually worsened! (See p. 40.)

In Year 2, we noted the possibility of a trend toward increased transfer of guardianship to siblings or other relatives. Data in the final two years do not confirm the existence of such a trend. Still, it is likely that the ages of the *Jackson* movers and the corresponding ages of their parents may have influenced their responses to the Family Survey.

CHAPTER 4

SURVEY RESULTS

This chapter analyzes results of the fourth year's mail survey questionnaire. It also compares them to those of Years 1 through 3. The analyses are direct comparisons of the responses for each of the four years, consistent with the original intent of our longitudinal approach.³

Bar graphs show survey results as percentages.

These "figures" are numbered to correspond with the questions in the survey instrument.

The Year 4 report shows the frequency distribution of the responses as bar graphs, followed by short explanatory narratives. The questionnaire itself is **Appendix A**. The findings are not presented in the same order as the questions were asked. Instead they are grouped to show relationships and facilitate comparisons between responses to related questions. Last year, in addition to these descriptive statistics and analyses, we proposed several hypotheses about relationships among a number of survey variables. This year we offer and test similar hypotheses (**Appendix B**).

Our findings are based on analysis of the data collected from four years of mailed questionnaires administered to the population described above, the last in June 1997. The data are organized to reflect the respondents' opinions and perceptions solicited through the survey instrument. They are grouped by the following subject categories:

- A. the parents' or guardians' satisfaction with the services their sons or daughters or wards received in the institution and are receiving now;
- B. the frequency of their visits to their sons or daughters or wards at their old and new homes;
- C. the parents' or guardians' assessment of the urgency of their sons', daughters' or wards' need for medical care (this is a "control" variable which the researchers hypothesized may relate to respondents' other opinions about the transition);
- D. perceptions about the State's and residential providers' handling of the transition;
- E. problems in *Jackson* clients' adaptation to their community environments;
- F. perceptions of changes in the sons', daughters' or wards' state of well-being; and
- G. perceptions about how their families' lives have changed since their sons, daughters or wards moved into community-based residences.

³ For many items (and for all items in sections F and G), we have also computed and report *average* percentages and "mean scores" across the entire four years of the Family Survey. The importance of these averages is discussed further in the introduction to section F, page 24.

A. Parents' and Guardians' Satisfaction with Services

Figure 4.3*

How satisfied were you with the services your son or daughter or ward received at Los Lunas or Ft. Stanton?

*Note: For all figures and tables, numbers and letters following the decimal refer to corresponding items in the survey instrument (Appendix A).

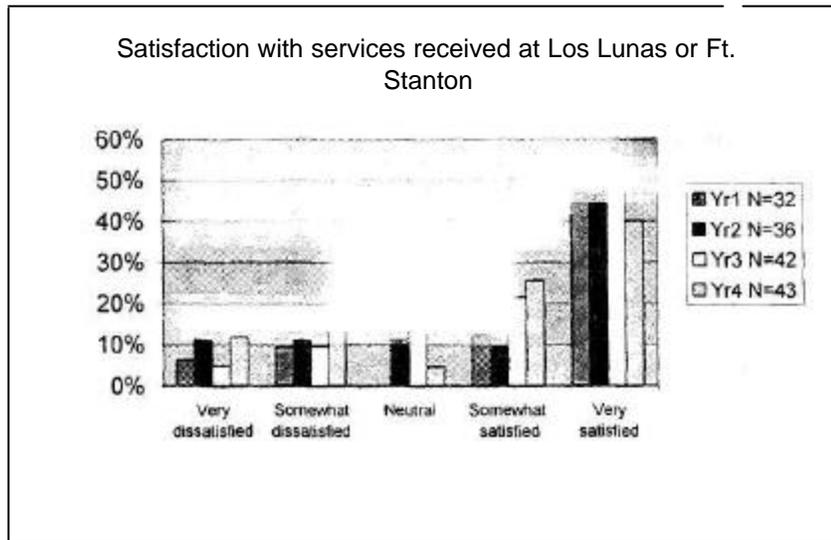


Figure 4.3 shows some initial variance between Year 1 and Year 2 responses regarding satisfaction with services that most respondents recalled their relatives had received in the institutions. At Year 2, a greater percentage remembered being *very satisfied* (56%) or *very dissatisfied* (11%) with these services. In Year 3, a little fewer than 70% of those who responded indicated that they were either *very satisfied* or *somewhat satisfied*. Of the remaining 30%, respondents were split: 15% were *somewhat* or *very dissatisfied*, and 17% reported being *neutral*.

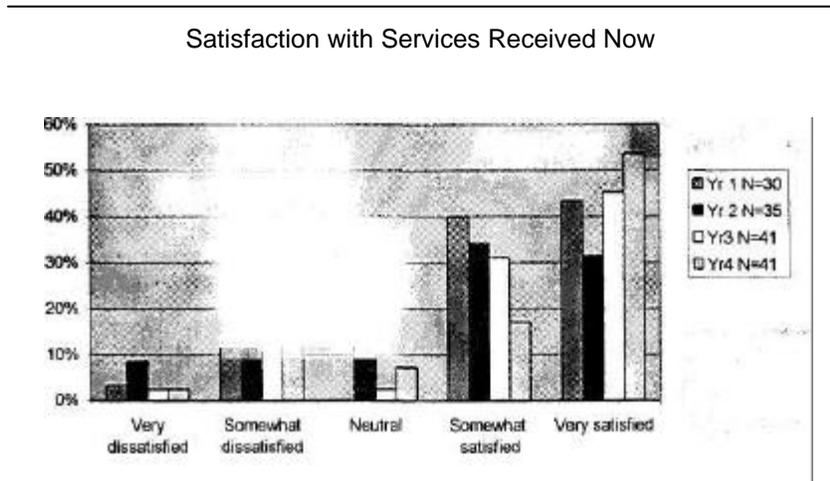
Parents' and guardians' opinions about the services that their relatives received in the institutions have become somewhat less positive over time.

In Year 4, opinion shifted markedly. (This is a benefit of having a four-year horizon to assess respondents' levels of satisfaction.) The most striking macroscopic observation is that respondents' opinions were distributed more bimodally in Year 4 - the number who were *neutral* decreased. About two-thirds said they were either *very* or *somewhat satisfied* with the services their relative received at Los Lunas or Ft. Stanton, the lowest level of satisfaction reported during the survey period. However, 31% reported being *somewhat* or *very dissatisfied*.

We suspect that after their sons, daughters, or wards left the institutions the respondents began to form new opinions about the experience, which changed as memories faded and they began to accept the reality of the new situation. The longer their relatives remain in the community, the less satisfied they recall being with the institutions. This finding supports our earlier proposition that for family members the process of adjustment is similar to that of the movers' - it takes time to adjust to the change.

Figure 4.7

Overall, how satisfied are you with the services your son or daughter or ward is receiving now?



Though most respondents are satisfied with the services their relatives are receiving, a significant minority is at least somewhat dissatisfied. The rate of dissatisfaction was highest in Year 2, but is almost as great in Year 4.

Figure 4.7 provides several interesting findings. There is general stability in the respondents' opinions across all four samples over time. However, respondents are increasingly somewhat polarized in their opinions, tending toward being *very satisfied* or *somewhat dissatisfied*, with few reporting being *neutral*. This "bipolar" distribution is characteristic of a number of responses to questions in this survey.

A strong majority of respondents in each year indicated they were *somewhat satisfied* or *very satisfied* **with the services their sons, daughters or wards** were receiving in the community-based residential settings. The combined rate of positive responses declined slightly in Year 4 but remained above 70%, while over half the respondents were *very satisfied*! Conversely, a significant and increasing minority each year reported being *somewhat dissatisfied*. The second year survey showed the highest combined rates of dissatisfaction and neutrality (34%), and the lowest rate of satisfaction (66%), suggesting that critical adjustments may have been taking place that influenced parents' or guardians' assessments.

In Year 4 the combined rates of dissatisfaction and neutrality totaled 29%. Thus, a significant minority of parents and guardians whose relatives have been in the community for several years are not making even mildly positive assessments about the services that their relatives are receiving in the community. This finding may be of interest to policy makers concerned with the viability of community placements over the long term.

B. Frequency of Parents' Visits at Institution and in the Community

Figure 4.5

How often did you visit your son or daughter or ward at Los Lunas or Ft. Stanton during the last five years?

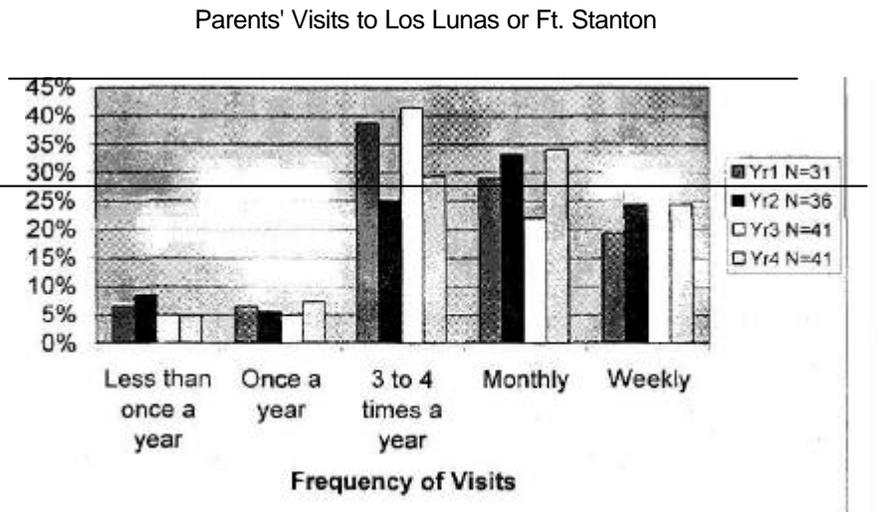


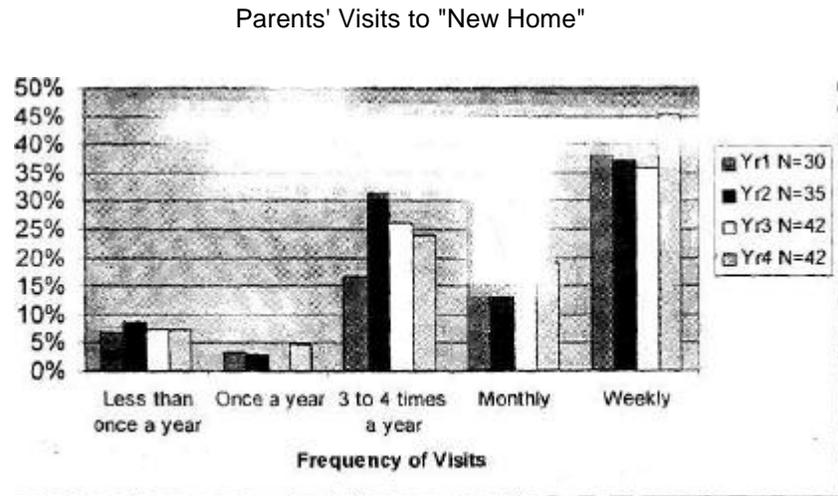
Figure 4.5 charts parents' or guardians' recollection of the frequency of their visits to their *Jackson Class* relatives during their last five years in the institutions. Though that recollection may be affected by time, the result should remain relatively stable. The graph largely confirms this. For the first and third years, nearly a majority (48 and 49%) stated they had visited their family member at least once a month, while for Years 2 and 4 the figure was higher (61 and 58%).

Over the course of the survey on average 6% of the respondents stated that they visited their son or daughter or ward at Los Lunas or Ft. Stanton less than once a year during the last five years, while another 6% indicated that they visited once a year. Over time 34% said they visited 3 to 4 times a year. (This is the highest average frequency of visits.) Almost 30% of the survey respondents said they had visited on a monthly basis, while nearly one-quarter (24.5%) indicated visiting on a weekly basis. Since it is reasonable to believe that the ability to recollect may be affected over time, by calculating the average percentages we capture some of the variance attributable to this potential problem.

These average percentages take on meaning when compared to the results of the following graph, **Figure 4.6**, which measures the frequency of visits (over time) to the relatives' "new" homes in the community.

Figure 4.6

How often do you visit your son or daughter or ward at his or her "new home" (community-based residence)?



The findings displayed in **Figure 4.6** are instructive. They allow us to compare the reported frequency of parents' and guardians' visits to their relative's new home in the community over the four years of the study. Comparing the data derived from the two figures (4.6 and 4.5) also provides an opportunity to examine the variance in the frequency of visits across the two very different living environments.

Rates of visitation in the community remain high and stable. The percent of respondents who indicated that they visited their *Jackson Class* relative at least once a month never fell below 57% (in Year 2). The percentage of respondents who reported visiting *-weekly* climbed in Year 4 to its highest level (46%).

Family members visit their Jackson Class relatives more often in the community than they did in the institutions.

On average over the duration of the Family Survey, not quite 8% of the parents or guardians indicated that they visited their relative in the new home in the community *less than once a year*, while less than 3% reported that they visited *once a year*. About 25% said they visited *3 to 4 times per year* in the community. Similarly, about a quarter of the respondents stated they visited their relative *monthly*. Finally, The mean percentage of survey respondents who said they visit their son, daughter, or ward at the "new home" in the community on a *weekly* basis was a strong 40%.

Even more telling is the **difference** in the aggregate rates of visitation (averaging all years' data) **between** the institutional and community settings. Table 4.1 summarizes the data.

Table 4.1

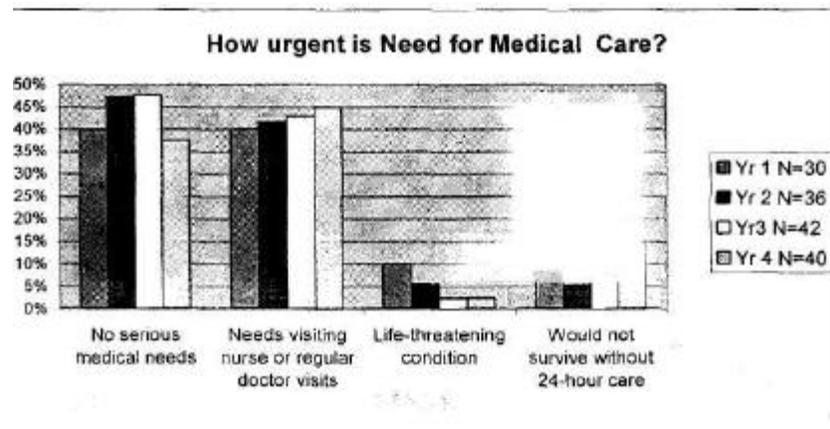
Visit Frequencies

	<i>Less than once a year</i>	<i>Once a year</i>	<i>3-4 times a year</i>	<i>Monthly</i>	<i>Weekly</i>
Visits in the Institutions	6%	6%	34%	30%	24%
Visits in the Community	8%	3%	25%	24%	40%

The basic finding shown by the table is that parents and guardians visit their *Jackson* class relatives with greater frequency in the community than in the institutions. We propose that convenience and proximity may account for much of the change, since many Jackson clients moved to their parents' home communities. (A few now live with their parents or other relatives.) Even those who don't live in their parents' communities may be more accessible to their family members or guardians because they are distributed throughout New Mexico rather than residing in either of two centralized facilities.

C. Need for Medical Care

Figure 4.8 How urgent do you consider your son's, daughter's or ward's need for medical care?



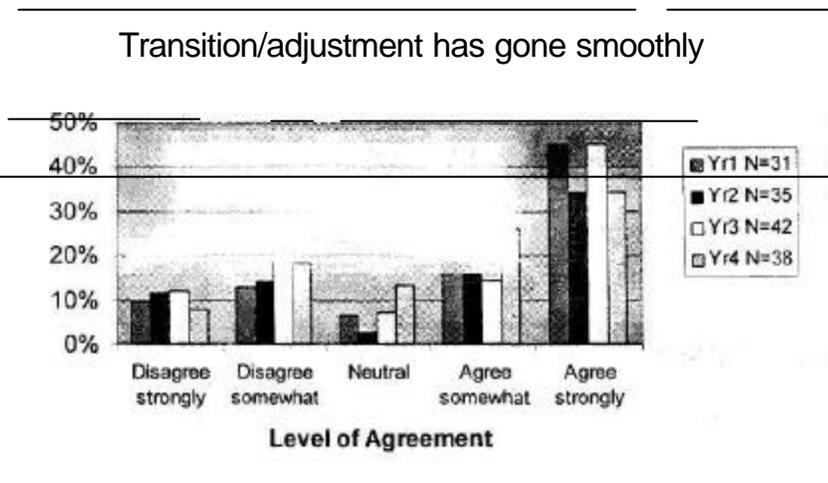
Parents' perceptions of their relatives' medical fragility have decreased. More medically fragile Jackson Class members are now living in the community. This explains why 15% in Year 4 report say that their daughter, son, or ward would not survive without 24 hour care.

In Year 1, 80 percent of the parents or guardians of the early movers believed that their son or daughter or ward did *not* have a life-threatening condition requiring rapid access to medical treatment or 24-hour medical care. In Year 2, almost 90% of the parents or guardians responded in this manner, and by Year 3, this increased to 91%. In Year 4, however, this percentage fell to 83%, which was unexpected, while the percent of respondents who believe their *Jackson Class* relatives would not survive without 24-hour care doubled from the previous survey. Still, the variances are small in terms of actual numbers, and reflect the fact that more medically fragile individuals have moved into the community in the later years of the *Jackson* transition process.

The data reported in Figure 4.8 show relatively *stable opinion over time*. Over the four years of the study, an average of nearly 43% of the respondents indicated that their daughter, son, or ward needs a visiting nurse or regular doctor's treatment. In light of the fact that more medically fragile individuals are now part of the *Jackson* population living in the community it intuitively makes sense that 15% of the respondents to Family Survey 4 indicate the need for 24-hour care. This observation lends some support to one of the propositions presented in earlier reports, namely, that parents' and guardians' *perceptions of their relatives' medical fragility decrease* after they observe them in the community-based residence for a longer time. In other words, most now see their sons or daughters or wards as being *less* dependent on the need for medical care, compared to when they resided in the institution.

D. The Transition Process

Figure 4.9b: "The transition process went as smoothly as our family expected" (Year 1) or "The adjustment of our relative or ward to the community living arrangement has gone as smoothly as our family expected" (Years 2 and 3).



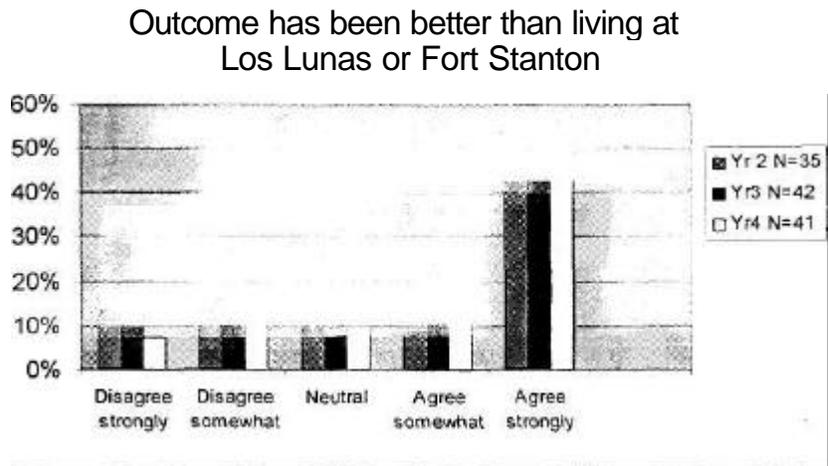
(Note that the survey question changed after Year 1. In Years 3 and 4 we used the same wording as in Year 2. Because both questions ask respondents to compare actual outcomes with their expectations, we believe the responses capture the same or closely related phenomena; thus we have included Year 1 responses in arriving at our findings.)

Over time, fewer respondents (but still nearly two-thirds) agree that the adjustment process went as well as expected.

Figure 9b shows the percentage of respondents agreeing (strongly or somewhat), and the percentage disagreeing (strongly or somewhat) with the statement that their relative's adjustment to the community went as smoothly as expected. There is some fluctuation from year to year, but examining the mean percentages over four years reveals that only about 10% of the respondents *disagree strongly*, and nearly 17% *disagree somewhat* with the statement. On average 26% *agree somewhat* with the statement that the adjustment went as smoothly as expected, and almost 40% *agree strongly* with the statement. The lowest mean percentage of respondents (about 7%) say they are *neutral*. The mean percentages do show over 65% of the parents or guardians agreeing that the adjustment of their relative or ward to the community living arrangement has gone as smoothly as the family expected.

Figure 4.9c

"Overall, the outcome so far ... has been better for my (our) relative or ward than living at Los Lunas or Fort Stanton" (asked in Year 2 and later).



In Year 4 a majority of the respondents (52%) *agree strongly* with the statement that the outcome of the transition from the institution to the community-based living arrangement has been better for their daughter, son, or ward than living in the institutions. An additional 16% *agree somewhat* with that statement. Favorable responses to this statement have increased incrementally over time.

Two-thirds of respondents agree that living in the community is better for their relatives than institutional living.

When average percentages for the last three years are examined (this survey item was added after Year 1) several distinct patterns become visible. For all years averaged, nearly 47% of the respondents indicated that they agree strongly with the statement, while another 15% of the parents or guardians said they agree somewhat. Parents and guardians neutral on the question averaged about 11%, and an average of less than 15% of the survey respondents *disagreed somewhat* or *disagreed strongly*. If the *neutral* responses are omitted, more than twice as many parents and guardians agreed that community living is better for their relative or ward than disagreed.

E. Problems Adjusting to Living in the Community (Years 2 and 3)

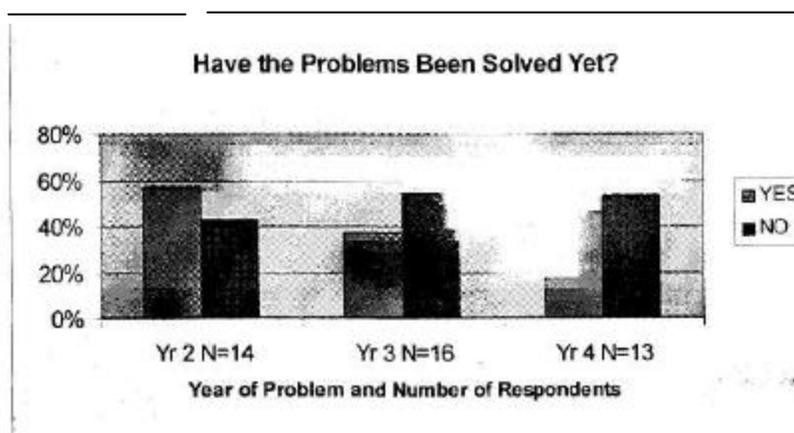
Nearly 2/3 of respondents say their relative has not experienced adjustment problems.

In every year except Year 1 we asked parents or guardians whether their relative or ward had faced any "major problems adjusting to living in a community residential environment." On average, 36% of the respondents indicated that their daughter, son, or ward had encountered problems adjusting to community-based living. (In Year 4 it was only 30%.) Stated more positively, combining all report periods, 64% of the respondents (and 70% of those responding in Year 4) said that their family member or ward *had not encountered major problems* adjusting to community-based living. (See **Appendix A, Q. 10a.**)

We then asked those respondents whose relatives had encountered adjustment problems whether or not the problems had been solved. The responses for Years 2, 3 and 4 are shown in **Figure 4.10c.** below. .

Figure 4.10c

"If he/she has encountered problems, have they been solved yet?" [asked in Year 2 and subsequently]



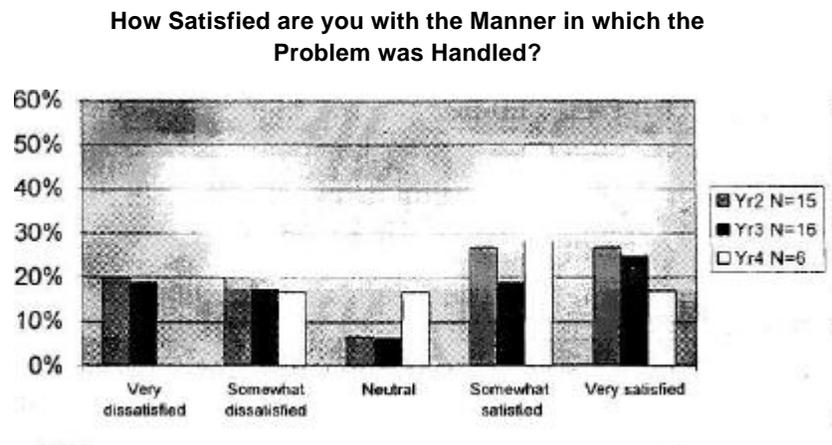
Of the minority of parents and guardians who report adjustment problems, over half say those problems have not been solved.

For the sub-sample of individuals who *did* report major problems in the adjustment process for their ward or family member an average of 57% over the three study periods indicated that the problems had *not* been solved. The relative stability of this number suggests a level of frustration among this subgroup that perceives that major problems have gone unaddressed. However, it is important to keep in mind that this figure represents just 19% of the total number of Family Survey respondents.

To explore the issue of problems and the solutions provided by the community-based service providers we asked those whose relatives or wards who had encountered problems how satisfied they were with the way the residential provider had dealt with them. The results are shown in **Figure 4.10d.**

Figure 4.1 Od

"How satisfied are you with the manner in which the residential provider has handled this (these) problem(s)?" [asked in Year 2 and subsequently]



Among respondents who identified problems, more than half were satisfied with the way the way they were handled.

Of the minority of parents and guardians who reported major adjustment problems in their relatives' or wards' community living situations during the three-year study period, on average only 13% were *very dissatisfied* with the way the problems had been handled. Another 23% were *somewhat dissatisfied*, while 10% were *neutral*. A clear majority of this subgroup was either *somewhat satisfied* (32%) or *very satisfied* (23%) with the providers' handling of the problems. It should be noted that even in some instances where respondents said adjustment problems had *not* been solved, they still indicated that they were satisfied with the residential providers' actions to handle the problems.

F. Perceptions of Changes in Jackson Class Members' Lives Since Moving to the Community

Indicators of perceived changes in the movers' lives are organized in three groups.

For this final report we examine trends for Years 1-4, and then present computed averages (mean percentages) for all responses over the course of the study.

Respondents rated each item on a scale, from "worse" to "better."

Figures 4.11 A. through L. below include the primary indicators chosen to measure parents' and guardians' perceptions of ways their *Jackson* Class relatives' lives have changed following their move from state institutions to new living arrangements in the community. As in the three previous reports, the responses are grouped into three categories for ease of comparison: measures that relate to **access**, measures concerned with **opportunities and choices**, and measures of **overall well being**.

In addition to a discussion of the responses for each category, following the presentation of graphs comparing Year 1, Year 2, Year 3 and Year 4 data, we present "average" responses (mean percentages) for most items over the entire four years of the Family Survey. For economy, the "positive" responses (*better* and *somewhat better*) are combined, as are the "negative" (*worse* and *somewhat worse*). We also present in footnotes, where appropriate, the "mean score" of all responses, based on the 1-to-5 scale used in the survey (discussed below), together with the "standard deviation." (a measure of "dispersal" from the mean).

Although the year-to-year trends continue to be of interest, averaging responses for all years provides a statistically important validation of parents' and guardians' perceptions of changes in their *Jackson* relatives' lives and their families' circumstances. There are three reasons for this. First, the sample size is much larger (N=153) than that of any of the single year samples. This lets us to be more confident of the validity of the data. Second, year-to-year variations or anomalies that may have been caused by temporary adjustment or residential provider difficulties (particularly at Year 2, as noted in the Year 3 report) are "smoothed" by averaging. Finally, potential errors caused by the variance in sample sizes over the four years are eliminated through this procedure.

In reviewing the findings presented here the reader should be aware of a source of *sample bias*, which is built into all mail survey questionnaires. This is *self-selection* bias. This means that people are more likely to respond to mailed questionnaires (and specific survey questions) when they feel strongly (either bad or good) about a specific issue or the subject of the survey. Thus, even calculating means across all the survey periods cannot allow us to say unqualifiedly that the sample responses "represent" the perceptions or attitudes of the entire population (the parents and family guardians *of all Jackson* class members).

For all items in this section of the questionnaire, we asked respondents to imagine a scale from 1 to 5, where 1 means things have changed for the worse, 5 means things have changed for the better, and 3 means things have not changed.

1. Access

Figure 4.11-A Access to medical services

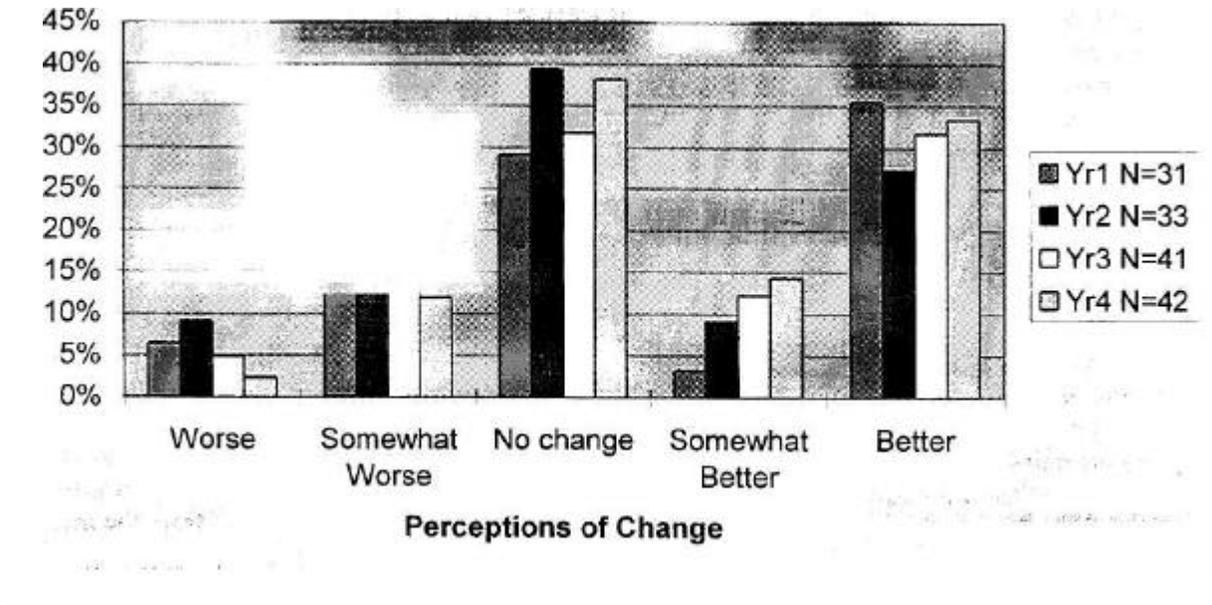


Figure 4.11-C Access to special therapies

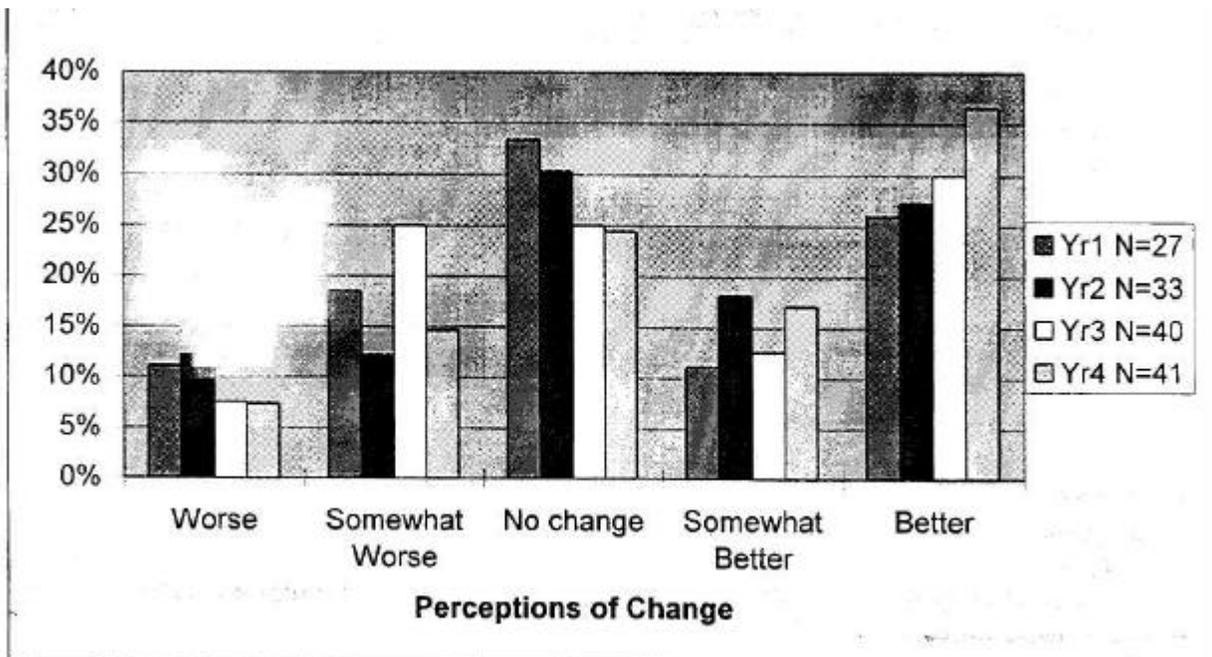


Figure 4.11-D Access to recreational activities

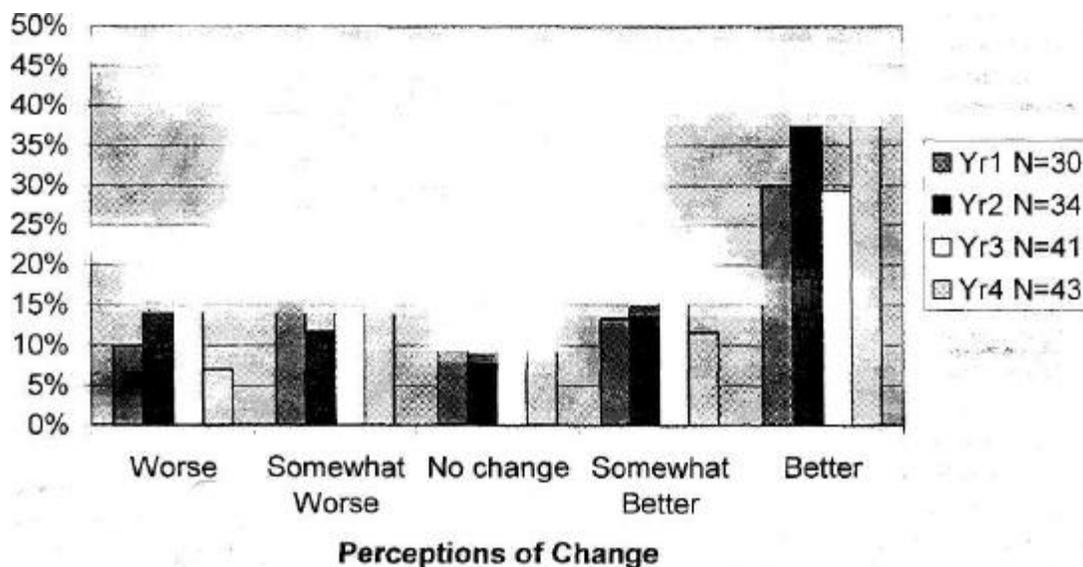
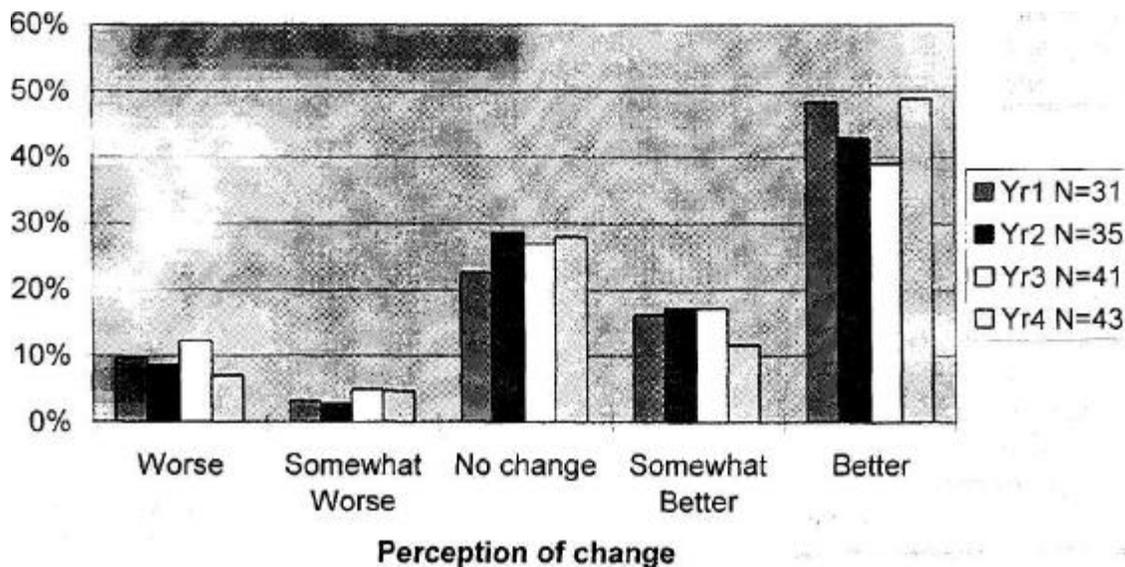


Figure 4.11-G Access to transportation



The wide range of opinions about access to medical services probably reflects real variations in the situations of individual movers.

Access to special therapies is seen as better each year, and by a clear majority of respondents in Year 4.

Access to recreational activities seems to be better for most movers but nearly a third of the respondents feel it is worse.

More respondents who indicated a perception of change, over time, stated that access to medical services, special therapies, recreational activities and transportation had *improved* than stated that it had *worsened* since their sons or daughters or wards had moved into a community-based residence. We first examine the variance over the specific time periods and then compare the average percentages.

Figure 4.11-A shows positive responses (i.e., *somewhat better* or *better* than in the institutional setting) ranging from approximately 35% to 48% over the four time periods, to our query about access to medical services. The percentage of parents or guardians stating that access to medical services was *worse* or *somewhat worse* declined somewhat over the four years (from 32% to 14%).

As we noted in earlier Family Survey reports, a significant percentage of parents and guardians responding (35% averaged over four years) report *no change* in access to medical services in the community-based living environment when compared to the institutional living arrangement. *On none of the other access questions is the neutral response as high.*⁴ This may be because parents and guardians have limited opportunity to observe whether access to medical services has changed. Those who do note change tend to view it as positive, as the upward trend over the four surveys suggests. The wide range of opinions on this issue suggests considerable variation in the individual circumstances of movers in the community setting.

For the individual years and the complete duration of the surveys we discover in **Figure 4.11-C** a more or less positive trend across all four points in time for the measure of opinion concerning movers' access to **special therapies**. By Year 4 a majority (54%) of respondents say access is *better* or *somewhat better*. The graph displays a downward trend for respondents indicating *no change* (from about 33% to 24%) as well as those finding access *worse* or *somewhat worse* (22% in Year 4). This movement in opinion may indicate that special therapies are becoming more accessible over time in the community. This seems quite reasonable in light of the fact that for many communities special therapy providers were not in place prior to the *Jackson* ruling.

At the initiation of the Family Survey several members of the pre-survey focus group indicated significant concern with regard to access to **recreational activities**. The underlying fear was that the movers would have limited access to recreational opportunities in the community-based residences as compared with the institutions. Over time the majority of survey respondents have indicated a much different perception, but a significant minority appeared to have their worst expectations fulfilled.

Mean score = 3.456; SD = 1.256. Medical access, access to recreation and access to special therapies rank among the lowest mean scores for perceptions of changes in movers' lives. See Appendix D.

From the data in **Figure 4.11-D** we discover that, on average over the four surveys, approximately 32% of the respondents viewed their relatives' access to recreational activities as *worse* or *somewhat worse* than in the institutions. Yet this same figure shows, on average, about 52% of the respondents who said access to recreational activities was *somewhat better* or *better*. As noted above, focusing on the mean percentages (averages) over the life of the project enables us to understand that positive perceptions outweigh negative ones. The rather wide band of deviation from the mean in Years 1 and 2 suggests some ambivalence in early opinions about whether recreational access was improving for most movers.⁵

Satisfaction with access to transportation is high (averaging 60% for the four survey periods).

Figure 4.11-G indicates that an average of 60% of the parents or guardians over all four surveys said that **access to transportation** had become *somewhat better* or *better* for their son, daughter, or ward after the move into the community. About 27% of the respondents to all four surveys perceived *no change* in access to transportation. Only 13% of the respondents, on average over the four surveys, thought that access to transportation had become *somewhat worse* or *worse*. Although this appears strongly positive, the dissimilarity of the community and institutional environments suggests transportation may not have been much of an issue where most services were provided within institutional walls, whereas availability of transportation is more critical to successful living outside. Thus the 40% of respondents who report *no change* or *worse* may actually be registering fairly strong criticism of the adequacy of their relatives' access to transportation.⁶

In summary, the annual survey data for the access indicators and the mean percentages calculated across the four years present a clear picture of parents' and guardians' perceptions of change. This picture is largely positive. For the indicators above, the majority of the respondents to our four surveys have perceived improved access for their daughters, sons or wards in the community living environment. Within this generally positive assessment, however, there is substantial criticism by a minority of respondents regarding their *Jackson* class relatives' access to some specific services.

Mean score for this item = 3.453. Standard deviation = 1.449.

Mean score for this item = 3.820, second highest of all the indicators for perceptions of changes in movers' lives. Standard deviation = 1.301.

2. Opportunities and Choices

Figure 4.11-E Frequency of recreational activities

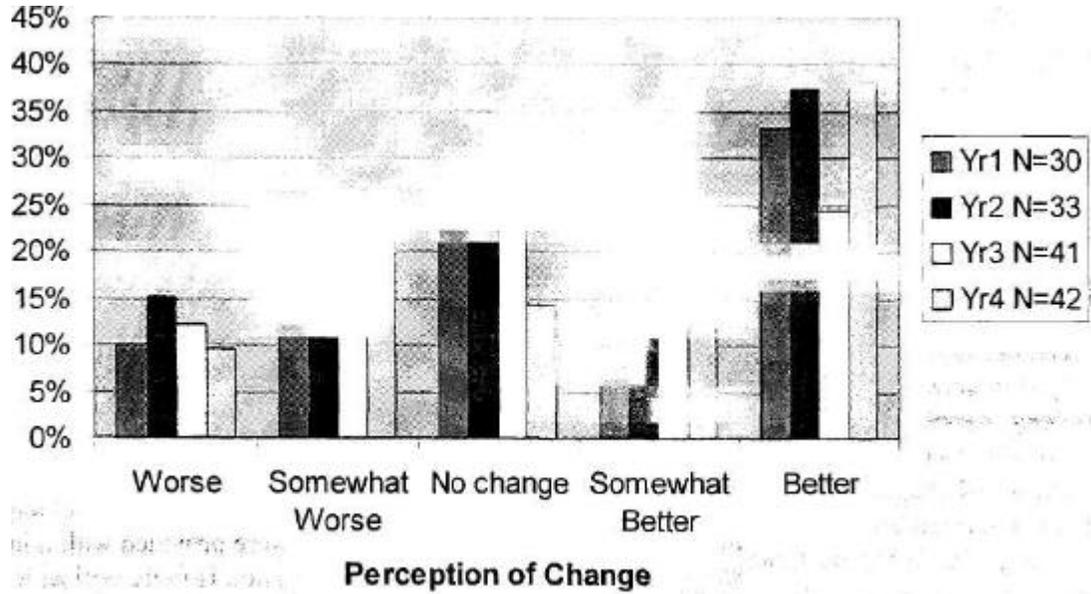


Figure 4.11-F Opportunities for social interaction

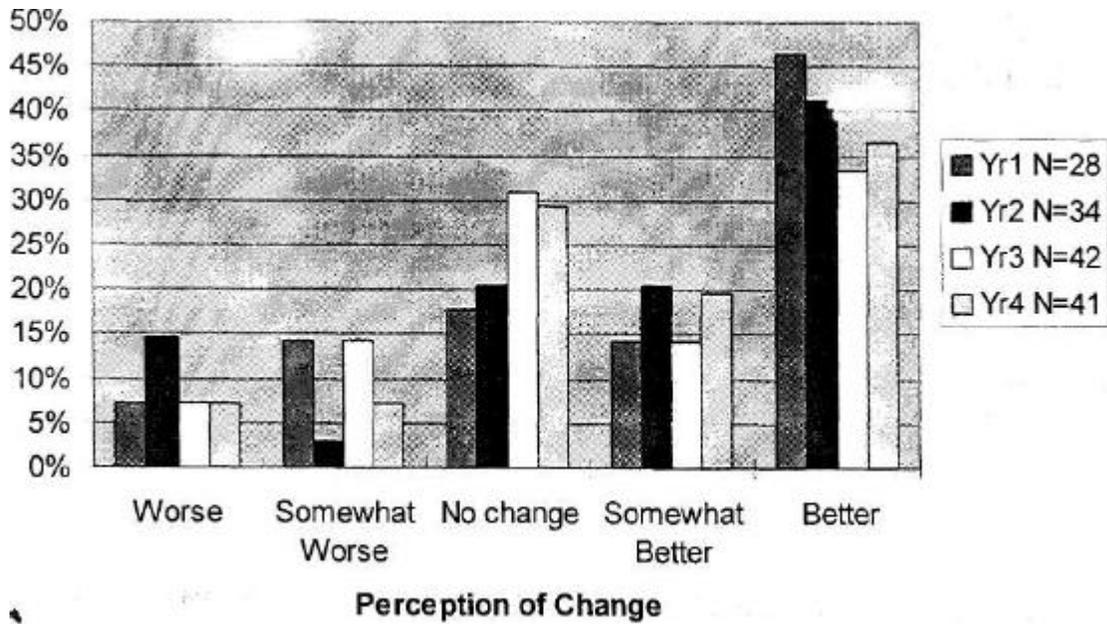
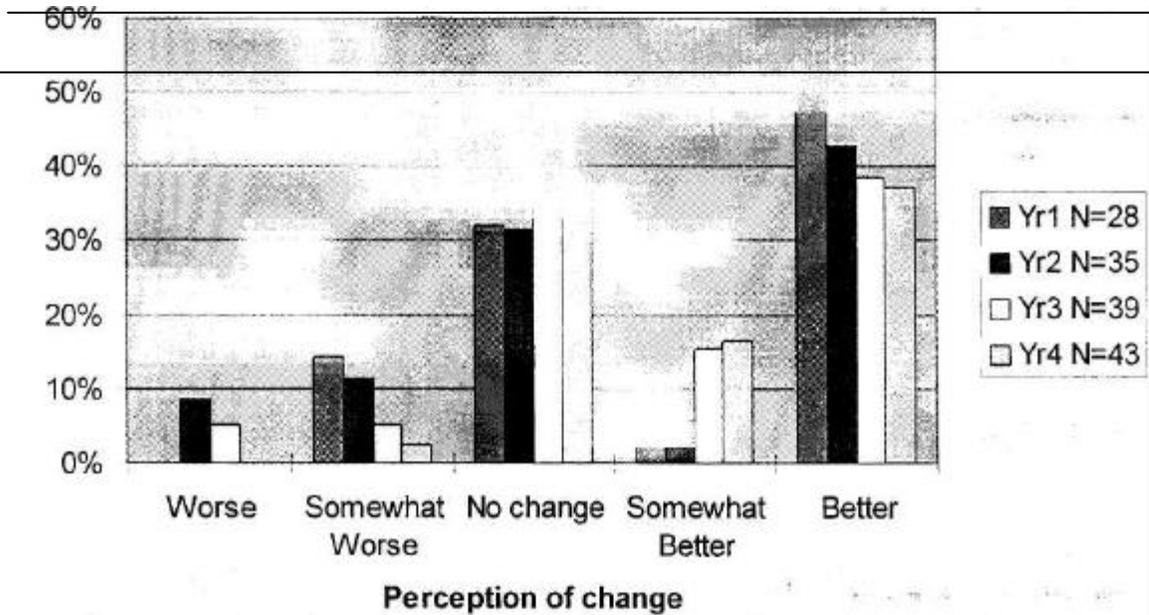


Figure 4.11-1 Opportunities to make choices



A primary benefit of moving from an institutional home to a community-based home is perceived to be the increased opportunities and freedoms for the movers to make independent or assisted choices. In this portion of the *Jackson Family Survey Final Report* we examine three different indicators - **Frequency of Recreational Activities, Opportunities for Social Interaction** and **Opportunities to Make Choices**.

Responses over time indicate that the frequency of recreational activities is improving for most, but not all, movers. Almost a third say that it's worse.

In **Figure 4.11-E** illustrates parents' and guardians' perceptions of the change in the frequency of their relatives' or wards' participation in recreational activities over the duration of the study. Our findings are mixed. The positive upward trend for the combined categories *somewhat better* and *better* continues, and at Year 4 these included a majority (55%) of our respondents. Yet 31% at the same time rated the frequency of recreational activities as *worse* or *somewhat worse*, an increase from Year 3, while those perceiving *no change* fell to 14%. We suggested in previous *Family Survey and Jackson Longitudinal Study* reports that a period of adjustment might be necessary while providers and movers learned about and were able to take advantage of recreational opportunities in the community. The more bipolar distribution of Year 4 data may indicate that, as perceived by an increasing minority of respondents, the frequency of recreational activities is indeed getting worse for a portion of the *Jackson* class population.

Calculation of mean percentages (averages) across the four surveys also supports the overall positive trend, while confirming that a significant minority holds contrary perceptions. 31% stated that participation in recreational activities was less frequent (*somewhat worse* and *worse*), while 48% indicated that it was more frequent (*somewhat better* and *better*).

In Year 4 more respondents see opportunities for social interaction improved, while a shrinking minority thinks they are worse than in the institutions.

In last year's *Jackson Family Survey Report* we noted that the parents and guardians responding were likely to have been more aware of **new opportunities for social interaction** between Year 1 and Year 2 than between Year 2 and Year 3. We thought that this might account for a nearly 15% drop in the percentage of individuals who viewed such opportunities as *somewhat better* or *better*.⁷ How does this observation hold up over time? **Figure 4.11-F** shows a substantial reversal of that "trend," with *better* ratings up by 9% and *worse* ratings falling by 7% to the lowest level of all four surveys. Computing mean scores for the five response categories to compensate for year-to-year anomalies may provide a more valid measure of opinion. A strong majority (56%) of the respondents, averaged over the life of the study, state that opportunities for social interaction have become *somewhat better* or *better*.

Most respondents' opinions about movers' opportunities to make choices are positive; only 10% over four years say things are worse.

The final question in this section attempts to measure parents' and guardians' perceptions concerning their daughters', sons' or wards' **opportunities to make independent choices**. The last time we examined this indicator (Year 3) we noted a general trend toward improvement over the time period. In the data shown in **Figure 4.11-1** we note a marked decrease in perceptions that choice opportunities are *worse*, yet an increasing percentage reports *no change*. More than one-third of the respondents in Year 4 stated that they have observed *no change* in their relatives' opportunities to make choices. (See the note below.)

Again, we suggest that the mean scores provide a more valid gauge of respondents' perceptions. More than 52% of the survey respondents, over the four years, say that their relatives' opportunities to make choices are *somewhat better* or *better*.

⁷ This suggests a potential methodological issue. Although the survey instrument asked respondents to compare the *current situation* with the *institutional setting*, some may have been thinking in terms of year-to-year comparisons. We have no way of knowing whether this has occurred or how much it matters. We believe that it would tend to raise the rate of *no change* responses in later years among some respondents who had noted improvement during the initial year their relative lived in the community. See note 17 in Chapter 5.

3. Health and Well-being

Figure 4.11-J Living environment

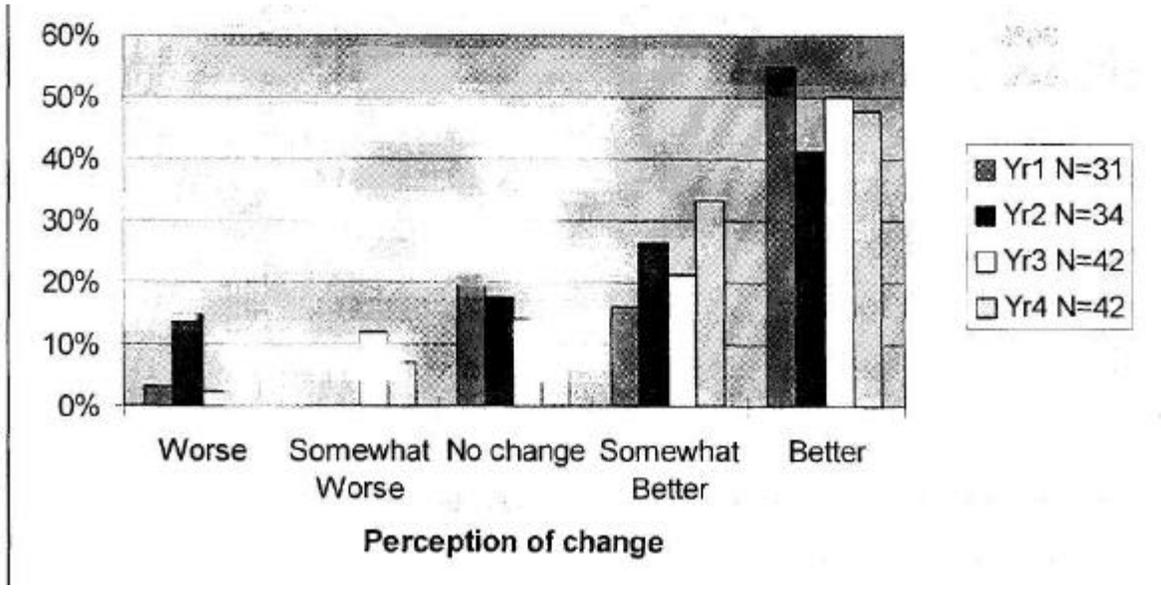


Figure 4.11-K Overall health

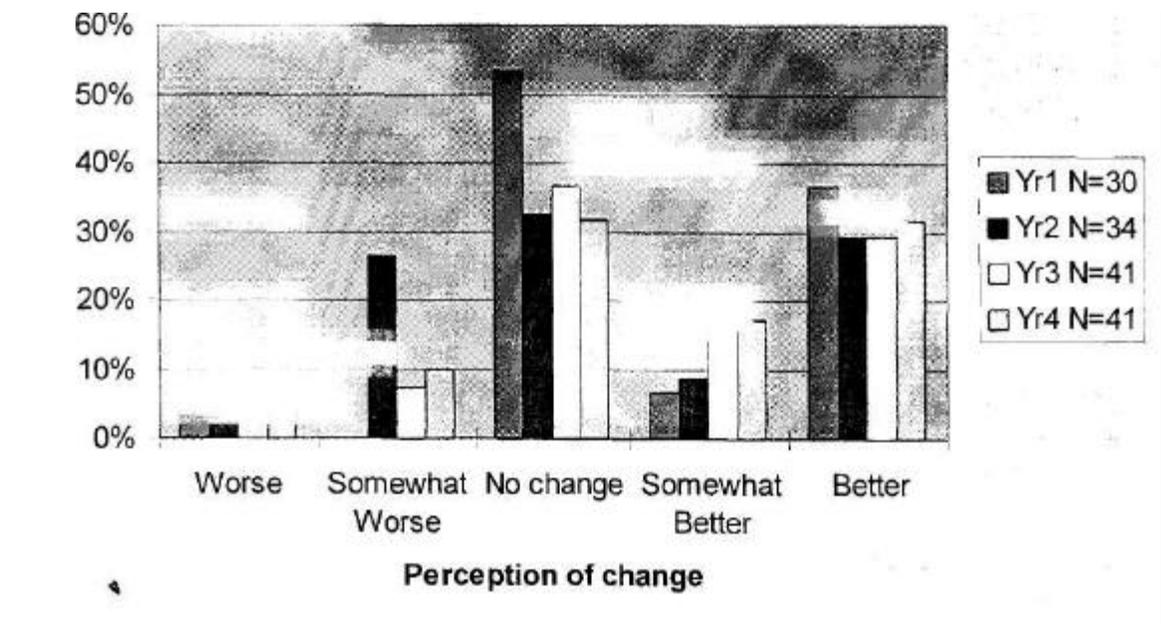


Figure 4.11-B Quality of medical services

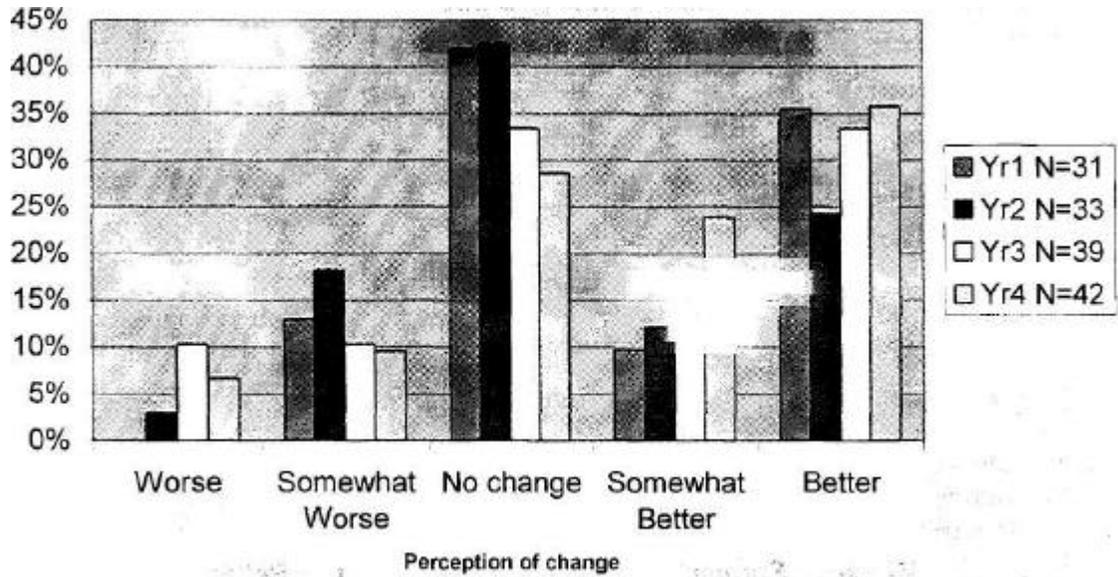


Figure 4.11-H Level of happiness

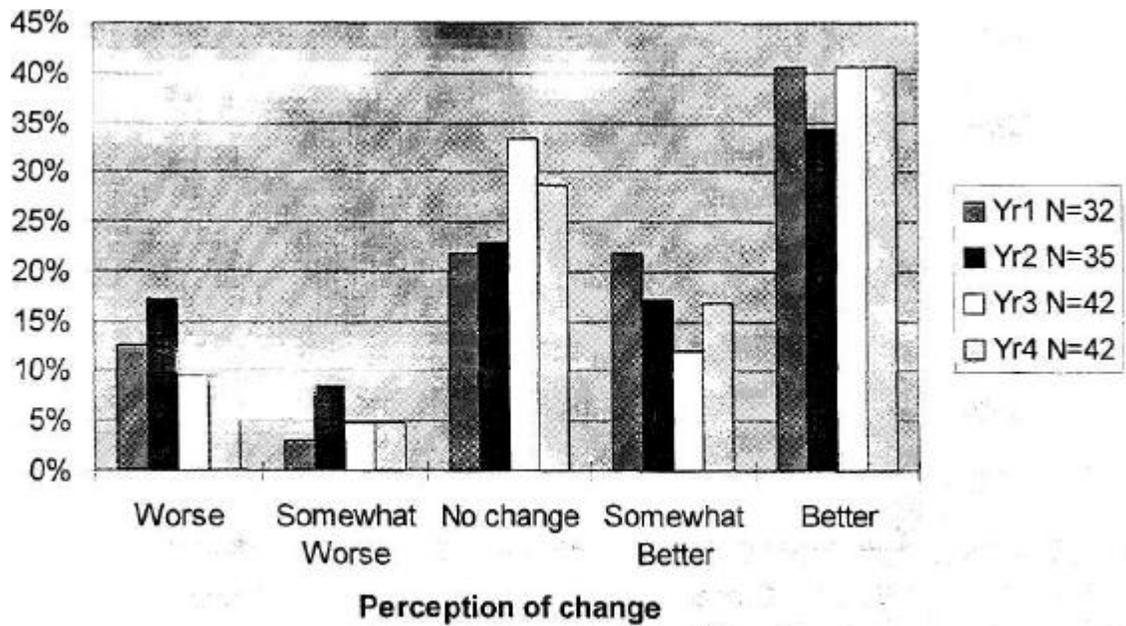
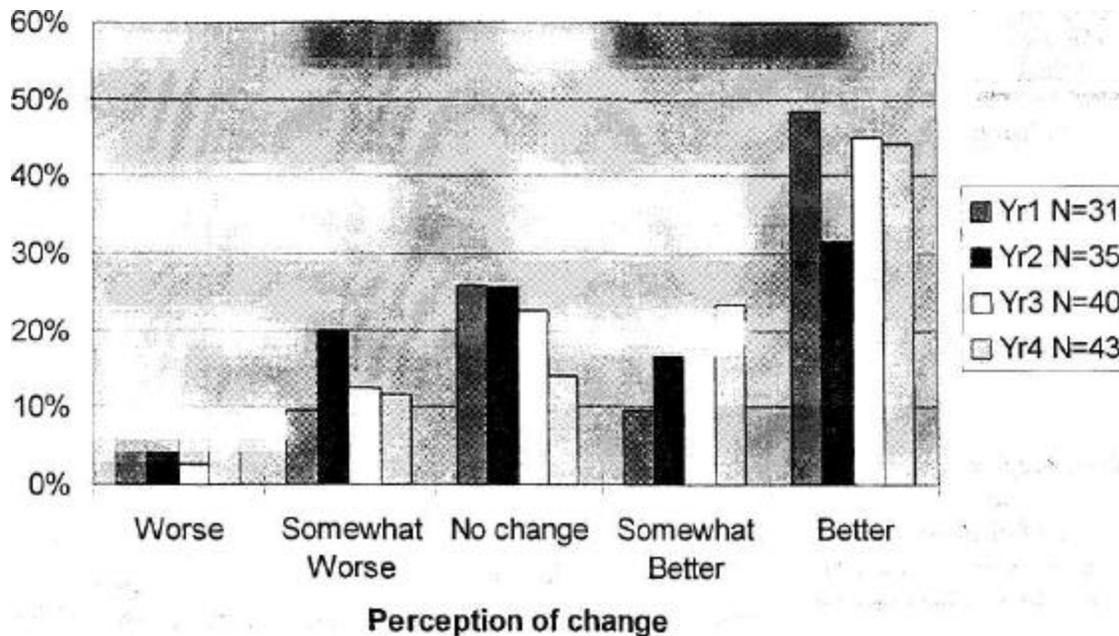


Figure 4.11-L Overall welfare and well-being



Responses to all indicators of health and well-being show improvement.

Of these indicators, "living environment" shows the most positive response.

Five indicators in our survey assess respondents' perceptions of changes in movers' **Health and Well-being**. They are "Living Environment," "Overall Health," "Quality of Medical Services," "Level of Happiness," and "Overall Welfare and Well-being." For all five indicators, for all four years, the Family Survey respondents indicate improvement in conditions for their family member or ward since moving into the community. A closer look shows some interesting variance among the indicators and across the samples over the four-year period.

The most positive response over time remains parents' and guardians' perceptions of their family members' **living environment** as shown in **Figure 4.11-J**. Responses for this indicator are overwhelmingly positive and increasingly so each year. In Year 4, 81% of survey respondents view the community living environment as *somewhat better or better*. Only 7% see *no change* in their relatives' circumstances, down from 26% at Year 1. This suggests that opinions have solidified over time. Four-year averages support this positive assessment of most of the community-based residential environments. 73% of all responses are *better or somewhat better*, while only 11% are *somewhat worse or worse*.⁸

⁸ Mean score = 4.040; standard deviation = 1.185. See Appendix D.

Over four years, almost half of the respondents see the overall health of the movers as improved.

Although **Figure 4.11-K** shows considerable volatility in the first two years of the survey, a trend toward a positive assessment of the **overall health** of respondents' family members is evident. Year 1 data presented an optimistic picture, and Year 2 perhaps reflected a reaction. In Years 3 and 4, opinions normalize, with 49% noting improvement (*better* or *somewhat better*) both years. In Year 3, 14% state that the health of their relative has worsened (at least *somewhat*). This rises to 20% in Year 4.

Health is a complex indicator, involving many variables beyond the quality of the residents' community living environment. This is not an experimental study and we have no control group against which to compare these findings. Thus we are unable to draw any firm statistical conclusions. However, the four-year averages do support the contention that the health of almost three times as many movers has (in our respondents' view) improved (45%) as has declined (17%).

Over the four years, most respondents see the quality of medical services as better or unchanged.

In Year 4 opinion continues to shift significantly as to quality of medical services, as **Figure 4.11-B** shows. Following a decline from Year 1 to Year 2 in those reporting that the quality of medical services had gotten *somewhat better* or *better*, by Year 3 the percentage of individuals indicating that the quality of medical services had improved for their son, daughter, or ward returned to the Year 1 level. By Year 4 the percentage of the combined *better* responses rises to 60%. There is a corresponding decline in *no change* responses in both years. (In Year 4 respondents reporting the quality of medical services as *somewhat worse* or *worse* fall to 17%.) Averages over the four years confirm that most parents and guardians feel the quality of medical services has improved (48%) or unchanged (36%).

Over half the respondents believe the level of happiness of their relative has improved, while another one-third say it has not changed.

Figure 4.11-H shows responses to the indicator for the family member's or ward's **level of happiness**. Over the four-year period more than 50% of the respondents for each year indicated that their relative's level of happiness since moving into the community was *somewhat better* or *better*. Although the Year 1 data show the highest positive response (63%), this may be attributable to the "halo effect" - enthusiasm about the initial community placement. A 10% "spike" in negative responses in Year 2 may reflect respondents' adjusting their expectations of life in the community. Over time positive opinions stabilize; the four-year average is about 56%. Negative responses (stating that their relatives' or wards' level of happiness is *somewhat worse* or *worse*) average 17%.

Most respondents view the movers' overall welfare and well-being as better, about one-fifth say it hasn't changed.

Finally, a plurality (Year 2) or majority (all other years) of respondents regarded the **overall welfare and well-being** of their relative as *better* or *somewhat better* (**Figure 4.11-L**). In Year 4, 67% offered positive responses. Only 19% said they felt their family member's overall well-being was *worse* or *somewhat worse* since he or she moved into the community. About 21% of all respondents (and only 14% in Year 4) said that the overall welfare and well-being of their relative had *not changed* since the move.

These reasonably strong positive findings are supported by the four-year average percentages. Over the entire period of the Family Survey, 60% of respondents reported the overall welfare and well-being of their relative was *better* or *somewhat better*, while less than 19% said it was *worse* or *somewhat worse*. It is interesting that this broad indicator registers more positive responses over time than do several of the narrower, more specific measures. Even if, for instance, an individual's health has declined, some respondents are likely to affirm that the mover's welfare and well-being has improved.

⁹ Mean score = 3.779; SD = 1.273. See Appendix D, which shows mean scores in decreasing rank order. The observation that general indicators of outcomes often rank higher than more specific measures is discussed further in Chapter 5 and substantiated in the additional analyses in Appendix B.

G. *Perceptions of Changes in the Lives of Families of Jackson Class Members Related to the Transition*

This set of indicators tracks changes in the lives of parents and guardians and their families.

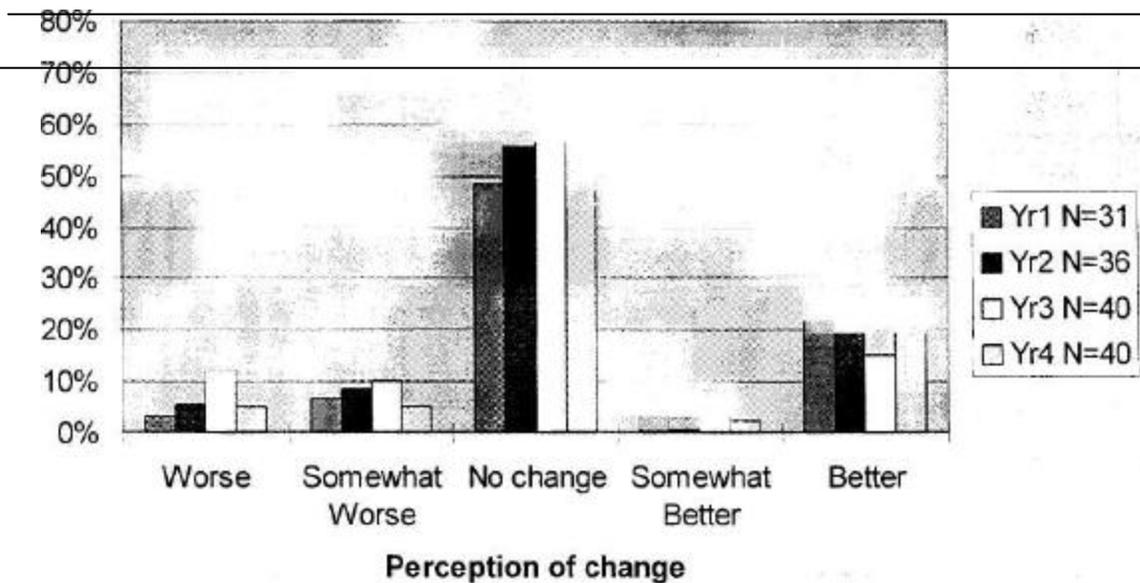
We have discovered that the Jackson process has not changed things for the families as much as for the movers themselves.

Figures 4.12 A through K show parents' and family member guardians' responses to indicators of changes in **their own lives** as they may have been affected by their *Jackson Class* family member's move to the community. Like the earlier multiple indicator figures, the responses are grouped in three categories to facilitate comparisons. These are perceptions about the **individual respondent's** life, the **family's** lives together, and the family's **relationships with their Jackson Class family member**. The same scale was used as in the previous section.

As we have noted in the three previous reports, respondents report some interesting **differences** of opinion between perceptions about their family members' or wards' lives and their own lives. First, responses seem to **vary independently** from parents' and guardians' perceptions of the quality of life of their *Jackson Class* family member. Second, for most indicators of family life, there is considerably less change over time. This suggests that, to an extent, their lives **have been and remain stable over time** regardless of the change in living environment for their son, daughter, or ward. Third, distributions continue to be less bimodal than they are for the data about the movers. (That is, more respondents report *no change* to most of these questions about family life, rather than responding at the ends of the scale - *better* or *worse*. This is not true for all indicators in this group, however.) Generally, "things" appear to have **changed** a good deal **less** for their families than for the *Jackson* clients themselves. Exceptions to this generalization are discussed below.

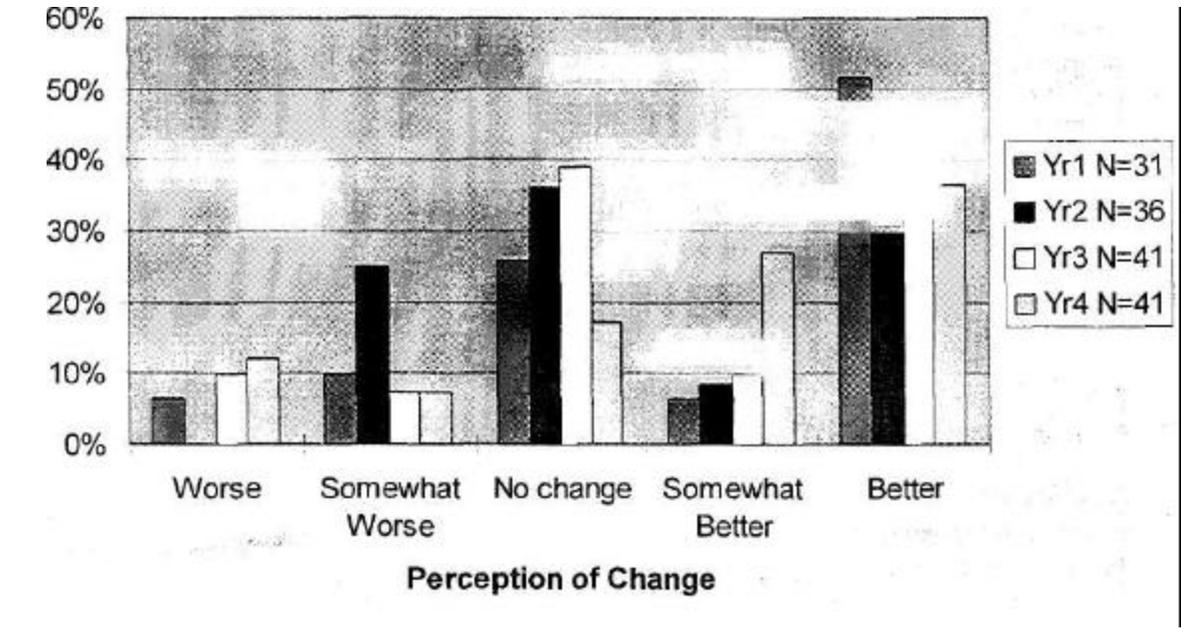
1. Individual Respondent

Figure 4.12-A Your own social life



(Text continues on next page.)

Figure 4.12 B Your level of happiness



Asked about "your own social life," most respondents' answers each year reflect no change.

Most respondents in every year of our survey indicated that their **own social life (Figure 4.12-A)** had *not* changed appreciably since their sons or daughters or wards moved into the community. Although in Year 1 42% reported their social lives were *better* or *somewhat better*, this may be attributed to a "halo effect" (indicating optimism about the initial move). Over time the *no change* response grows - to 68% in Year 4.

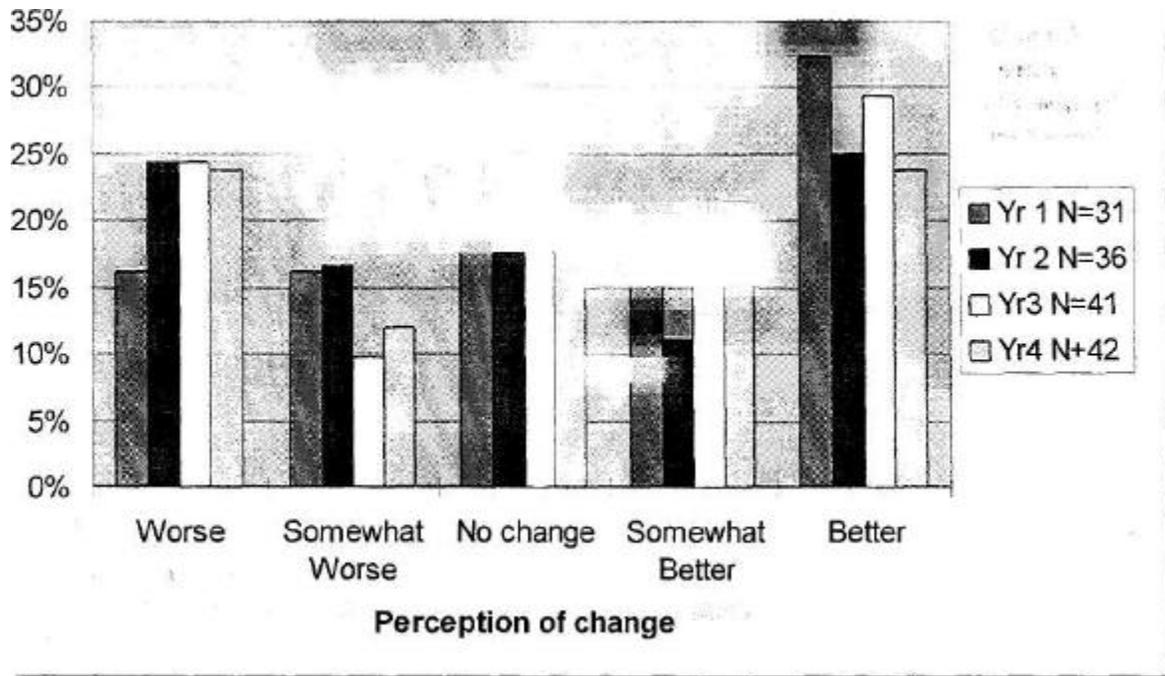
Once again the averages for the four years may provide the most valid measure of opinion. *No change* averages 58% of the responses. Among those reporting a change, about twice as many respondents say their own social lives are *somewhat better* or *better* (28%) as those who indicate it has become *somewhat worse* or *worse* (14%).

Considering their own "level of happiness," respondents' opinions varied from year to year but moved toward "no change."

Your level of happiness, on the other hand, is more volatile. The data in **Figure 4.12-B** suggest the "halo effect" may have been a factor in Year 1 for this indicator, while a "rebound" to negative and *no change* responses may have been at work in Year 2. The percentage agreeing with the statement that their own level of happiness had become *somewhat worse* or *worse* over time varies very little. What is striking is how the upward trend in *no change* responses we observed through Year 3 drops abruptly from almost 40% to only 17% at Year 4, while 64% report their level of happiness as *somewhat better* or *better*.

Given this volatility, the large sample four-year averages provide a more valid perspective. Over the course of the study 51% of responses are in the *better* direction, while 30% report *no change*.

Figure 4.12-J Your level of worry



"Your level of worry" about respondents' relatives remains quite stable over the study. For a significant portion, the level of worry has worsened.

That parents and guardians of *Jackson* Class movers have some **level of worry** (Figure 4.12-J) about the welfare and well-being of their sons or daughters or wards can be taken as a given. As with the previous indicator (your level of happiness), a Year 1 "halo effect" may have been offset in Year 2 by a "rebound" toward greater worry. Except in Year 2, however, a plurality of the respondents indicates that their level of worry has become *somewhat better* or *better* since their family member or ward moved into the community. This is tempered by the consistently significant minority (ranging between 32% and 42%) who report that their level of worry has become *somewhat worse* or *worse*.

Responses to this indicator are bimodal. Averaged over the course of the study, those reporting *no change* in their level of worry are only 20% of the respondents. While 44% indicate their level of worry is *better* or *somewhat better*, fully 36% say it is *somewhat worse* or *worse*. Clearly, many who feel their relatives' or wards' overall health and well-being, or their own happiness, have improved are still worried about the ultimate results of the community placement.¹⁰

The mean score = 3.135, the second lowest in the study. The standard deviation = 1.501, the widest dispersal of scores. See Appendix D.

2. Family Members

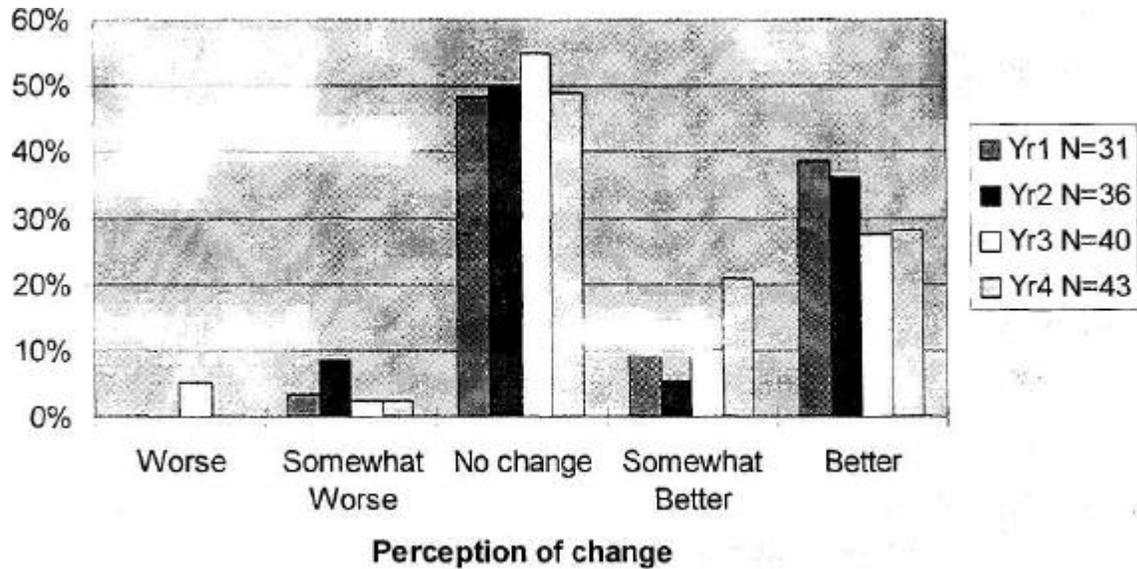
*Impacts on family life
have been generally
positive, to the extent they
have been significant at
all*

Perceptions related to the impact of the *Jackson Class* member's move on the family system remained quite stable in Year 4. When respondents indicated changes relating to their families, those changes were generally more positive over time. However, the primary dynamic we observe over time for most indicators is *no change*. This general pattern may relate to the fact that many of the parents and guardians are older. Since their other sons or daughters are now adults, a change in the status of their *Jackson Class* family member may not have as many implications for the other members of the family.¹¹ (See the discussion of the respondents' ages in Chapter 3 above.)

Overall, the stability of perceptions measured by these five indicators tends to suggest that for the families of most *Jackson Class* members "life just goes on." Although the parents' "level of worry" discussed just above is significant, and may be particularly so for some older respondents, it doesn't seem to have affected family relationships adversely. (We suggested in earlier reports that worry may relate to parents' or guardians' ages and their sense that they may soon lose the ability to monitor what is becoming of their relative or ward. It would be tempting to try to correlate respondents' ages with the level of worry, but did not ask this question in conducting the Family Survey.)

¹¹ This demographic fact also clearly affected the low response rate and possibly the high *no change* responses to the indicators your job and your spouse's job over the course of the Family Survey. In this final report we have omitted discussion of these items.

Figure 4.12-B Your family's relationships



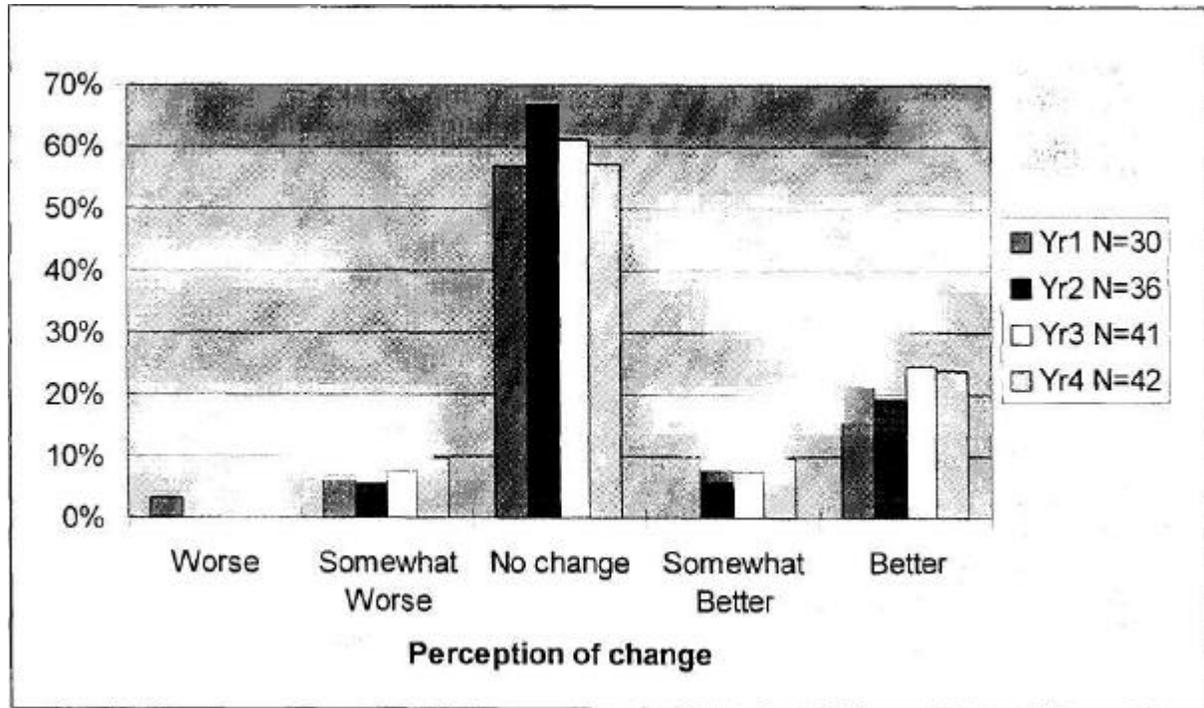
For many, their relative's move was seen to strengthen the family's relationships, particularly in the first year.

On this indicator (**Figure 4.12-B**), the evidence continues to suggest that a sizable minority of respondents associate the transition of their family member with strengthening family ties. A higher percentage do so at Year 4 than at any time since Year 1 (49% in both years). An equal percentage at Year 4 report *no change* occurred in their **family's relationships**. Remarkably, responses in the *worse* direction all but disappear.

These results are predictably stable. Averaged over the four survey periods, most (51%) of respondents reported no change; 44% reported *better* or *somewhat better* family relationships, and only 5% said things had gotten *worse* or *somewhat worse*.

This indicator produced one of the highest mean scores (=3.693) and narrowest standard deviations (=1.010) in this series of items. See Appendix D.

Figure 12-H Your time with other family members



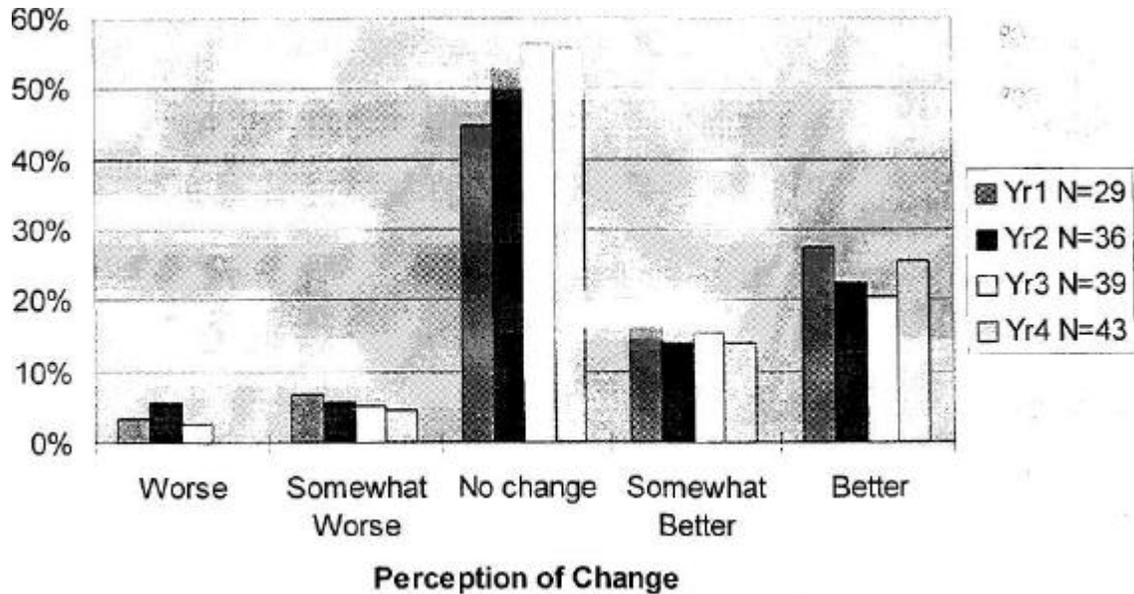
Again, time with other family members was little affected by the move.

Remarkable stability of opinion is noted over time for this question. Between 57% and 67% of the respondents indicated that there was *no change* in the **time spent with other family members** in light of their relatives' or wards' transition to the community. (Figure 4.12 H). *Better* and *somewhat better* responses spike at Year 1 and drop or moderate at Year 2 (supporting the "halo effect" - "rebound" pattern noted in some other items) **but** return to almost the Year 1 level at Year 4. They are about 3 times as high as responses in the *worse* direction.

Viewed over the entire course of the four surveys, the averages are typical of the responses in this section of the survey. *No change* accounts for 60% of the responses, *better* and *somewhat better* for 32%, and *somewhat worse* or *worse*, 8%. It is reasonable to suggest that the *Jackson* transition process has not caused any major modifications in time spent with other family members for most respondents during the four years of the Family Survey.¹³

¹³ Mean score = 3.466; SD = 0.948. See Appendix D.

Figure 4.12-G Overall quality of family life



For most respondents, overall quality of family life has improved or remained stable since the move.

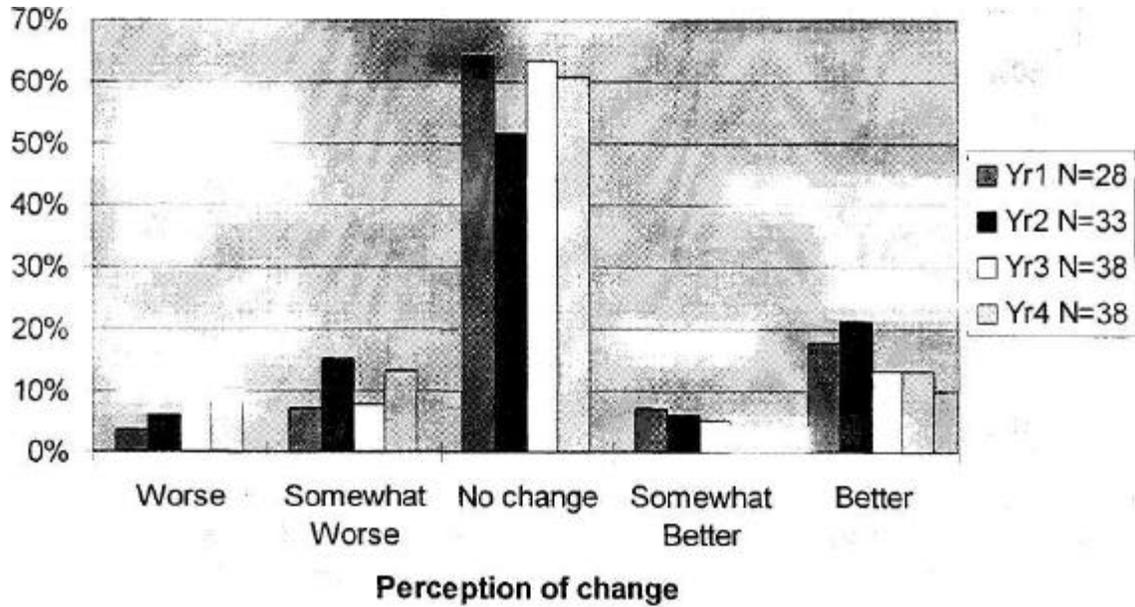
Figure 4.12-1 further substantiates the findings above, reflecting consistency of opinion with regard to the impact of the move into the community on the family system. Over time there is a slow and incremental growth (45%-56%) among those respondents indicating *no change* in the **overall quality of family life**. It is interesting to note that in each year, over one-third of the respondents (40% in Year 4) states that the overall quality of family life has become *somewhat better or better*. *Worse* and *somewhat worse* responses dwindle over time to 5% at Year 4.

Four-year averages are typical of the **family** series. *No change* responses are 53%, *better* and *somewhat better* are 39%, and *worse* and *somewhat worse* are 8% of all responses.¹⁴

¹⁴ Mean score = 3.517; SD = 1.002. See Appendix D.

3. The Family's Jackson Class Member

Figure 4.12-1 Your expenses for your Jackson Class family member



For most families, expenses for their Jackson Class family member haven't changed since the move.

A clear majority of respondents over time (52% -64%) indicated *no change* in their perception of their out-of-pocket expenses **for their Jackson Class family member** since the move (Figure 4.12-1).

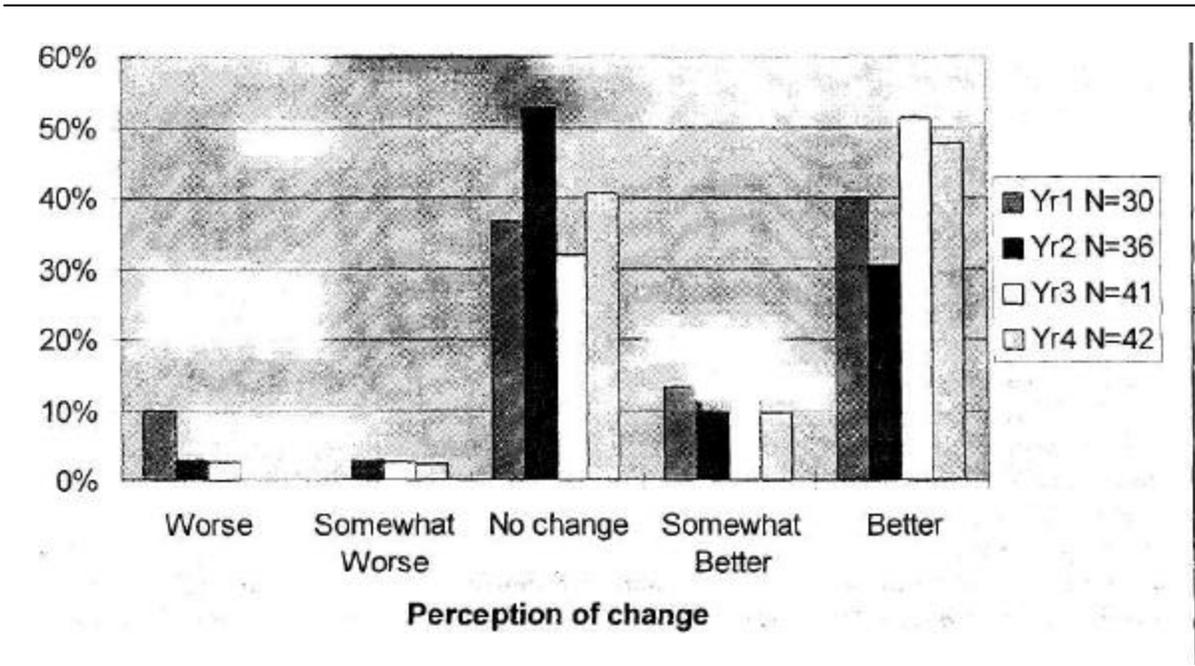
Of those who reported a change, an interesting pattern has developed. At Year 1, 25% reported their expenses were *somewhat better* or *better*, while only 11% said they were *worse* or *somewhat worse*. By Year 4, however, this pattern was inverted. *Somewhat worse* and *worse* perceptions had risen to 24% while *better* and *somewhat better* had fallen to 16%. This is the only indicator in the survey for which the negative responses outnumber the positive ones (and it is only evident at Year 4). This trend could be significant if it suggests that parents' and guardians' expenses are rising over time. The small numbers involved don't permit us to draw a firm conclusion.

The four-year averages do show, however, that the percentage of respondents who reported their expenses decreased (i.e., were better) (21%) and the percentage who said their expenses increased (19%) were very close.¹⁵ A separate study might determine the extent to which parents and guardians are contributing more financial resources to their Jackson class family members as time goes on.

Mean score - 3.126; SD = 1.033. This is the lowest mean score in the survey.

Figure 4.12-K

Relationship with your Jackson Class family member



Relationships with their Jackson Class family member have improved for a majority of families.

In Year 1, about 56% of the respondents indicated that their **relationship with their Jackson Class family member** was *somewhat better* or *better* since the move (Figure 4.12 K). This improvement was significant, particularly in light of the small (10%) negative response to this indicator. In Year 2 we noted an increase in the response category *no change*. We suggested this might reflect a perception that the relationship is beginning to "normalize" with the passage of time.

In Year 3 it became evident the variance in Year 2 was *not* indicative of an overall trend. Rather, in Year 3, responses indicating *no change* decreased from 52% to 32%. At the same time, there was a dramatic shift from *no change* opinions to *better*. In fact, 63% of respondents at that point reported their relationships to be *better* or *somewhat better*. This dropped somewhat at Year 4 to 58%, still a strong majority.

As has been the case with the other indicators, the four-year averages are likely to be the most valid measures, and the finding here is strong. *Better* and *somewhat better* constitute 54% of the responses, while 40% reported *no change*. Only 5% of the responses indicated the relationship was *worse* (none in Year 4) or *somewhat worse*¹⁶

¹⁶ Response to this indicator ranks as the highest mean score in this series (= 3.858), with a standard deviation = 1.082.

CHAPTER 5 KEY FINDINGS AND CONCLUSIONS

The fundamental question underlying both the Family Survey and the *Jackson* Longitudinal Study remains: "**Are the Jackson Class members' quality of life and satisfaction better in the community than in the institutions?**" If 153 responses from 70 families over four years represent the opinions of parents and guardians of the movers, the answer for most is unequivocally "Yes."

The final Family Survey report uses two perspectives: year-to-year trends and "global" mean scores. In a longitudinal study, the more data points there are, the more confidence we can have in the findings.

Our concern in this final Family Survey report is to provide accurate and reliable general findings and interpretations over the complete period of the investigation. As discussed at the beginning of Chapter 4, our analyses of the data are presented from two different perspectives. We first presented the fourth year findings and compared them to the year-to-year trends for the prior three years. But in addition, we computed and reported mean (average) scores based on all four years of the survey in order to control for sampling inefficiencies and self-selection biases. These findings are more global and are not "time-bound" like the individual, annual trends for prior years. They show the "bigger picture," a macroscopic overview of the opinions of the complete pool of parents and guardians responding to the annual mail surveys.¹⁷

Key findings

1. According to the respondents, opportunities and choices for *Jackson* Class members have improved. One of the cornerstones of the "deinstitutionalization" movement is the assumption that more individual choices are available in the community-based living environment. This proposition is confirmed over the course of our analyses. This is especially represented in the improved mean score

¹⁷ This picture may be slightly muddled by a methodological problem we did not anticipate. (See note 7 on page 31.) The instrument items were designed from the perspective of analyzing respondents' perceptions from a comparative point of view. Specifically, we asked the respondents to compare the present situation with the institutional setting. We believe, however, that some of them may have read the instructions to mean that they were to compare the situation during a given year in the community environment to that in the previous year. (After the first year an individual moved into the community, this would also have been in the community). This possibility might "contaminate" the data to the extent that the baseline comparative unit of analysis was not the institutional residences; rather, for an unknown number of individual respondents, the baseline may have "rolled over" each year. The effect of this, given the overall positive direction of the responses, is likely to have increased the rate "no change" answers. To this extent, the findings reported here may *understate* somewhat the improvement noticed by our respondents from the institutions to the community.

responses to the "global" question asking about movers' "opportunities to make choices." However, on one specific item in this series, "frequency of recreational activities," the response is more mixed (as shown by the lower mean score and the wide dispersal of scores). This is consistent with the *Jackson* Longitudinal Study (JLS) Year 4 finding that movers are far less likely to participate in physical activities requiring planning (such as swimming) and more likely to watch television than they were in the institutional setting. It appears our respondents are saying that opportunities are generally much better, but at least in this particular sector, not as good as they might be.

2. Our respondents believe that "access" - to special therapies, recreational activities, medical services, and transportation - has improved, rather than worsened, since their relatives moved into the community. This primarily positive macroscopic finding suggests that initial fears expressed by the focus group concerning the possible lack of access in the community were not validated over time. *How much* access is seen to have improved varies from one service to another, with access to special therapies showing the least, and access to transportation the greatest, improvement.
3. In considering the items associated with the movers' wellbeing, the respondents gave their highest mean score to the changes in their relatives' living environment. In descending order by mean score, the majority of respondents next ranked overall welfare and wellbeing, level of happiness, the quality of medical services, and the health of their relatives, as improved in the community-based residential environment. This global finding is strong indicator of parental and guardian satisfaction with the outcome of the transition from state institutions to the movers' new homes. Interestingly, responses to the more general indicators score higher than responses to the more specific ones.
4. The battery of questions related to the respondents' own lives and their families' relationships tend to indicate that the movement of *Jackson* Class members to the community has not had a major impact on the survey respondents' and their families' lives. This indicates the adaptability of parents, guardians, and their families to the new living arrangements. Furthermore, it suggests that while families are inherently concerned with their *Jackson* Class member they are able to continue in their day-to-day routines just as other families do when a member relocates or changes residences. This is not to minimize the difficulties - both practical and psychological - associated with the changes and adjustments their relatives underwent during the transition; rather it confirms the universality of such experiences.

5. Along this same line of reasoning, our global (mean score) measures do indicate that parents and guardians are still worried about the welfare and wellbeing of their son, daughter, or ward. When we remember the ages of many of the respondents this finding is more than reasonable. Significant numbers of parents and guardians worry about who is going to care for their relatives when they are no longer capable of advocating for them or monitoring the work of the residential and service providers. (In open-ended comments - reproduced for Year 4 in **Appendix C** - the issue is often put in terms of wondering whether the state will continue to provide resources at a level that can sustain the gains the movers have made to this point.)
6. The underlying contextual perception is one of optimism and approval, despite numerous instances in which survey respondents report dissatisfaction with specific situations. Parents and guardians responding to the Family Survey over four years have not been hesitant to express criticism of particular incidents or situations where their own relatives have received less than adequate care or services. Nonetheless, this has not prevented them from reporting general satisfaction regarding the improvement in their relatives' living environment and overall quality of life. The lesson to be gleaned from this seems to be that although parents feel community **living** "works," attention needs to be paid to situations where the actual provision of care and services does not rise to what the *best* practices show is possible.

Identifying what makes some community residential situations better than others is beyond the scope of this study. For instance, we did not directly collect data regarding particular providers (although we can identify them in many instances). However, it is possible to make some inferences about the meaning of associations between some of the indicators within the Family Survey. We have attempted to do this in a limited way in **Appendix B**. This appendix indicates the kinds of additional analysis that might be done with the data. It would also be possible to import data (such as ICAP scores and other demographic information) from the JLS, and to attempt to correlate this with information that the parents have reported about their relatives' success in the community environment.

APPENDICES

APPENDIX A: SURVEY INSTRUMENT (YEAR 3)

APPENDIX B: PROPOSED HYPOTHESES FOR ADDITIONAL ANALYSIS

**APPENDIX C: OTHER COMMENTS (OPEN-ENDED RESPONSES)
(YEAR 4)**

APPENDIX D: DESCRIPTIVE STATISTICS (MEAN SCORES)

;Nota! Este cuestionario es disponible en español.
Llame al 505 898-6015 para obtener una copia.

JRB ASSOCIATES USE ONLY

Questionnaire #4- _____

Date Received: _____

Date Entered: _____

**NEW MEXICO DEVELOPMENTAL DISABILITIES PLANNING COUNCIL
JACKSON LONGITUDINAL STUDY
FAMILY SURVEY**

This is a survey of families or guardians with a relative or ward who is a *Jackson Class* member. Please try to answer each question. Sometimes you may feel that you can not give an exact answer. There are no right or wrong answers. Please provide *your* best answer. Your *opinion* is important. Please answer the questions and return the questionnaire as soon as possible in the enclosed stamped return envelope.

All answers will be confidential. Thank you in advance for your assistance.

-
- 1. Did you respond to the Family Survey questionnaire last year?** Yes No
- 2. What is your relationship to the *Jackson Class* member?** (*Check all that apply.*)
- Mother
- Father
- Other (Please Specify): _____
- 3. Please provide this basic information on the *Jackson Class* member who is your relative or ward:**
- a. Age at which she/he first entered a residential institution: _____ (years.)
- b. Age today: _____ (years.)
- c. Month and year she/he moved from the institution into the community: _____, 199__
- 4. Overall, how satisfied were you with the services your relative or ward received at Los Lunas or Ft. Stanton?** (*Circle one response.*)
- | | | | | |
|----------------|--------------------|---------|-----------------------|-------------------|
| Very satisfied | Somewhat satisfied | Neutral | Somewhat dissatisfied | Very dissatisfied |
|----------------|--------------------|---------|-----------------------|-------------------|
- 5. How often did you visit your relative or ward at Los Lunas or Ft. Stanton during the last five years?** (*Circle one response.*)
- | | | | | |
|--------|---------|----------------------------|-------------|-----------------------|
| Weekly | Monthly | Three to four times a year | Once a year | Less than once a year |
|--------|---------|----------------------------|-------------|-----------------------|
- 6. How often do you visit your relative or ward at his or her "new home" (community-based residence)?** (*Circle one response.*)
- | | | | | |
|--------|---------|----------------------------|-------------|-----------------------|
| Weekly | Monthly | Three to four times a year | Once a year | Less than once a year |
|--------|---------|----------------------------|-------------|-----------------------|
- 7. Overall, how satisfied are you with the services your relative or ward is receiving now?** (*Circle one response.*)
- | | | | | |
|----------------|--------------------|---------|-----------------------|-------------------|
| Very satisfied | Somewhat satisfied | Neutral | Somewhat dissatisfied | Very dissatisfied |
|----------------|--------------------|---------|-----------------------|-------------------|

8. **How urgent do you consider your relative's or ward's need for medical care?**
(Check only one.)
- Would not survive without 24-hour medical personnel.
 - Has life-threatening condition that requires rapid access to medical care.
 - Needs visiting nurse and/or regular visits to the doctor.
 - Generally has no serious medical needs.
9. **Thinking about your relative's or ward's experience so far with life in the community, indicate your opinion about the following statements: (Circle one response.)**
- a. **"The level of services provided during the transition and since then has *not* fulfilled the promises made to our family."**
- | | | | | |
|-------------------|-------------------|---------|----------------------|----------------------|
| Agree
strongly | Agree
somewhat | Neutral | Disagree
somewhat | Disagree
strongly |
|-------------------|-------------------|---------|----------------------|----------------------|
- b. **"The adjustment of my (our) relative or ward to the community living arrangement has gone as smoothly as our family expected."**
- | | | | | |
|-------------------|-------------------|---------|----------------------|----------------------|
| Agree
strongly | Agree
somewhat | Neutral | Disagree
somewhat | Disagree
strongly |
|-------------------|-------------------|---------|----------------------|----------------------|
- c. **"Overall, the outcome so far of the *Jackson* process has been better for my (our) relative or ward than living at Los Lunas or Ft. Stanton."**
- | | | | | |
|-------------------|-------------------|---------|----------------------|----------------------|
| Agree
strongly | Agree
somewhat | Neutral | Disagree
somewhat | Disagree
strongly |
|-------------------|-------------------|---------|----------------------|----------------------|
10. **If your *Jackson Class* relative or ward has been living in the community less than four months, please skip this question and go on to Question 11.**
- a. **Has your relative or ward had any major problems adjusting to living in a community residential environment since his or her placement last year?**
- Yes No (If "No" please skip to Q. 11.)
- b. **Please briefly describe the problem(s).**
- c. **If he/she has encountered such problems, have they been solved yet?** Yes No
- d. **Overall, how satisfied are you with the manner in which the residential provider has handled this (these) problem(s)?**
- | | | | | |
|-------------------|-----------------------|---------|--------------------------|----------------------|
| Very
satisfied | Somewhat
satisfied | Neutral | Somewhat
dissatisfied | Very
dissatisfied |
|-------------------|-----------------------|---------|--------------------------|----------------------|
11. **The following questions ask about how you think your *Jackson Class* relative's or ward's life has changed since his/her move into the community. (See next page.)**

Imagine a scale from 1 to 5, where "1" means things have changed for the worse and "5" means things have changed for the better. If you circle "3" it means things have not changed. Please circle the appropriate response.

	Worse		Same	Better	
a. Access to medical services	1	2	3	4	5
b. Quality of medical services	1	2	3	4	5
c. Access to special therapies	1	2	3	4	5
d. Access to recreational activities	1	2	3	4	5
e. Frequency of recreational activities	1	2	3	4	5
f. Opportunities for social interaction	1	2	3	4	5
g. Access to transportation	1	2	3	4	5
h. Level of happiness	1	2	3	4	5
i. Opportunities to make choices	1	2	3	4	5
j. Living environment	1	2	3	4	5
k. Overall health	1	2	3	4	5
l. Overall welfare and well-being	1	2	3	4	5

The questions below ask how you think your family's life has changed since your relative or ward moved into a community-based residence.

12.

On the same scale from 1 to 5, where "1" means things have changed for the worse and "5" means things have changed for the better, please mark the appropriate response.

	Worse		Same		Better
a. Your own social life	1	2	3	4	5
b. Your family's relationships	1	2	3	4	5
c. Your level of happiness	1	2	3	4	5
d. Your job	1	2	3	4	5
e. Your spouse's job	1	2	3	4	5
f. Your opportunities for recreation	1	2	3	4	5
g. Overall quality of family life	1	2	3	4	5
h. Your time with other family members	1	2	3	4	5
i. Your expenses for your Jackson Class family member	1	2	3	4	5
j. Your level of worry	1	2	3	4	5
k. Relationship with your Jackson Class family member	1	2	3	4	5

13. Do you have adequate opportunities to discuss your problems and concerns related to your relative's or ward's move with other parents or families of Jackson Class members?

Yes

No

14. Please feel free to provide other comments or information you would like to share about your family member's move. (Use the space below or a separate piece of paper).

✎ Please check to make sure you have answered all relevant questions, and thanks again for taking the time to complete the survey.

✎ Please tell us how long it took you to complete this survey. _____

✎ Please return the questionnaire in the enclosed envelope.

The Year 4 Family Survey Report will be available by October 1, free from the Developmental Disabilities Planning Council (1-505-827-7590). If you would like a copy, check this box. —————>

APPENDIX B

ADDITIONAL ANALYSES

More advanced, bivariate analyses are reported in this appendix. These analyses are used to test several basic hypotheses and provide exploratory tests of associations among the variables (answers to questions) of parents' and guardians' perceptions. Generally, these analyses tend to substantiate our simple univariate descriptive statistics and the more generalizable mean scores (**Appendix D**) presented for the first time this year in this final Family Survey report.

The first correlation matrix presented below (**Table B-1**) correlates parents' and guardians' *level of worry* with their perceptions of the *overall welfare and wellbeing* of their sons, daughters, or wards in the community. A correlation coefficient of .727 indicates a very strong association between the two variables. In other words, in about 73% of the cases (responses) a parent's or guardian's level of worry *did* correspond with her perception of her relative's welfare and wellbeing. On page 40 (note 10) we observed that the mean score for the *worry* indicator was relatively low (approaching neutral), and that the dispersal of scores was very wide, with 36% saying it was worse or somewhat worse. Even though the overall welfare and well being were generally rated high, those respondents who rated it low tended to worry most about their relatives.

Table B-1

Correlation Matrix		Your w orry	w elfare/w ell-being:
Your w orry		1.000	.727
w elfare/w ell-being:		.727	1.000

144 observations were used in this computation.
9 cases were omitted due to missing values.

Confidence Intervals			
	Correlation	95% Low er	95% Upper
Your w orry, w elfare/w ell...	.727	.640	.796

144 observations were used in this computation.
9 cases were omitted due to missing values.

Table B-2 below examines the association between perceptions about whether *the outcome so far...has been better* (page 21) with a variety of other variables. The most striking finding is the relatively strong relationship between outcome scores and the respondents' perceptions of both the movers' *happiness* and their *own happiness*. We hypothesized that perceptions of the movers' happiness would be associated with respondents' opinions about the outcome. We also hypothesized that the outcome would affect the respondents' own happiness. The strong correlation coefficients (.749 and .726) substantiate this hypothesized relationship.

Relationships of outcome to the other variables shown are also interesting. The association is not quite so strong with the mover's *overall health*, which we might expect since the movers' health is subject to extraneous variables not associated with the move. Most interestingly, the respondents' perceptions of the outcome are *not* strongly associated with their perceptions of the quality of their relationship with

their son, daughter, or ward. This is intuitively satisfying to the extent that most parents' or wards' relationships with their *Jackson Class* relative will not depend on their perceptions of the outcome of the transition into the community. Many other causal factors influence this association.

Table B-2

Correlation Matrix						
	Outcome (Yr 2)	Happiness	Health:	Your worry	Your happiness	Relationship--s/d/w
Outcome (Yr 2)	1.000	.726	.648	.661	.749	.417
Happiness	.726	1.000	.696	.676	.666	.579
Health:	.648	.696	1.000	.702	.640	.428
Your worry	.661	.676	.702	1.000	.780	.497
Your happiness	.749	.666	.640	.780	1.000	.524
Relationship--s/d/w	.417	.579	.428	.497	.524	1.000

111 observations were used in this computation.
42 cases were omitted due to missing values.

The final correlation matrix (**Table B-3**) examines the association between the parents' or guardians' level of *satisfaction with the services your [relative] is receiving now* and a variety of other indicators (variables). The associations are not very strong between parents' and guardians' satisfaction with services and the other broader indicators of either their *level of worry* or their *own happiness*. The strongest association (correlation coefficient of .63) is between the respondents' perceptions concerning their level of satisfaction with the *welfare and wellbeing* of their family member or ward. The weakest association is between the perceptions of satisfaction with current services and *their relationship with their Jackson Class relative*. (As noted above, we would expect this relationship to vary independently of measures relating to the "success" of the move.)

These findings support our conclusion in Chapter Five, point 6: regardless of their complaints about specific situations (e.g., services in the movers' community homes), the Family Survey respondents are still more likely to find the overall outcomes of the deinstitutionalization process - the community living arrangements - preferable to the institutional ones. Additionally, these findings support the contention that the parents and guardians are able to make critical and differential assessments of the effects of the move on various aspects of the quality of their relatives' lives. Parents have things to say about these matters to which policy makers and implementers would do well to pay attention.

Table B-3

Correlation Matrix						
	Satisfaction w/ home	Your worry	Living envir	welfare/well-being:	Your happiness	Relationship--s/d/w
Satisfaction w/ home	1.000	.509	.565	.630	.529	.360
Your worry	.509	1.000	.657	.746	.785	.504
Living envir	.565	.657	1.000	.748	.680	.481
welfare/well-being:	.630	.746	.748	1.000	.754	.522
Your happiness	.529	.785	.680	.754	1.000	.526
Relationship--s/d/w	.360	.504	.481	.522	.526	1.000

138 observations were used in this computation.
15 cases were omitted due to missing values.

APPENDIX C
FAMILY SURVEY: "OTHER COMMENTS"

Ctrl: **Comment codes: 2 3 8**

Other Comments: ___'s move was the best thing for him. I have seen a remarkable improvement. He is definitely happier and healthier today than he was in Los Lunas. ___ has gained almost 24 pounds in two years that he has been home. He has touched many people in his community, has become a favorite with those that worked with him. I would like to say the same for the rest of his family. We have been very effected by this move. Our lives have changed remarkably. Our home is no longer ours. What we took for granted is gone. What a price for one's happiness. I don't regret bringing ___ home. We have enjoyed him so much and love him dearly. I just wish we could have seen into the future, and done things a little different. (Does it matter to anyone) Family members, Mom, Dad, brothers & sisters were never considered in these transitions.

Ctrl: **5** **Comment codes: 6 8**

Other Comments: The level of care my daughter receives on any given day depends on the staff present on that day. Right now her house supervisor _____, is great. She is a wonderful, warm and loving person. When she moves on we will be at square one -- yet again. I have known one provider that gets away with medicare and medicaid farud with the help of a very good attorney.

Ctrl: **9** **Comment codes: 8**

Other Comments: We are very concerned about the budget cuts that have occurred in '96 and in '95. There seems to be no recourse for families. I requested a fair hearing 12/1/95. It still has not happened. My letters have gone unanswered!!

Ctrl: **18** **Comment codes: 37 8**

Other Comments: Our son was doing well and happy in Ft. Stanton. When we were told that we had no choice and he would be moved out, we cooperated the best we could. It has taken over two years of frustrating changes and adjustments to get to the recommendations of the original TIDT, and he is now doing quite well in his community program. The State is now talking about a reduction of services which we will strongly and legally, if necessary, oppose. We warned that these reductions would eventually come, but were assured that the "community programs" would save great sums and cannot be cut.

Ctrl: **19** **Comment codes: 17**

Other Comments: My daughter's adjustment to community living was smoother than anticipated. The provider has done a fair job. However, I know that as long as I am in good health and able to "fight" for my daughter's needs she will be taken care of. But who will "fight" for her and see that she receives the care she needs and is entitled to when I am no longer able to meet with providers. I felt much more secure and felt that she would be taken care of after I am no longer able, at the Los Lunas Hospital and Training School.

Comment codes: 4
22 Ctrl:

Other Comments: My understanding with the community placement at the time when I was told that my son will move out of LLHTS was very satisfying, but it's different now- some of the major things that need to happen is not taking place. The whole environment is not at all satisfied. There is no modification been done at his house. Very dangerous slope on back yard; ground not level. My son sometimes moves around w/ wheelchair. **Comment codes: 8**

25 Ctrl:

Other Comments: Your survey does not cover home based living (family support living). Your survey does not cover day programs, which I have a severe problem with. I have had problems since day one [of?] my son's transition to now over day programs. Survey does not cover DRP's or [end of comment] **Comment**

codes: 3
32 Ctrl:

Other Comments: ___ is happier than he has ever been before. His mind is at ease knowing he has a home of his own as well as a home here with me.

Ctrl: **38** **Comment codes: 8**

Other Comments: It is good to have ___ here so that I don't need to travel to Los Lunas and I can keep a closer check on his well-being. I should, but time constrains, visit more often. Tresco is very good for keeping me informed and it's easier to go to meetings here.

Ctrl: **40** **Comment codes: 2 3**

Other Comments: My son ___ has been over 1 yr in the community new home. He is very happy in his new decorated home, loves his job and recreation, going shopping [and] bicycle riding. I am very happy with my son's move; I don't worry like I used to.

Ctrl: 41 Comment codes: 4

Other Comments: The move for mild retardation persons to community settings is good. But multiple handicap people and special needs people were served better at Los Lunas.

Ctrl: 42 Comment codes: 2 3

Other Comments: My relative has improved a great deal in all areas regarding his well-being. He seems to be much happier and it shows in his attitude and behavior.

Ctrl: 48 Comment codes: 46 8

Other Comments: See attached letter to Judge Parker. [Describes seemed happiness of daughter at LL, where she had lived for thirty years, compared to problems in community, including being caught in fights among other housemates, quality of care, and developing an ulcer. Notes case manager has been helpful, but CM's promotion means another change.]

Ctrl: 61 Comment codes: 8

Other Comments: Providers have a tendency to let things slip until we have to remind them to do their job. It took 2 years to get the right providers and the right staff.

Ctrl: 69 Comment codes: 4

Other Comments: I am unhappy about ___'s housemate. This girl is very mean to ___. One girl was already moved once, no here's another one and she's still at ___'s home and still hitting her. This girl is ___'s problem— ___ needs physical therapy and swimming like she had at Los Lunas. Her home should be calm and happy like I was promised.

Ctrl: 70 Comment codes: 7 8

Other Comments: Trying to cut the budget has put a pinch on his necessities. Recently they have asked us for bus fares and clothing, shoes, etc. I'm retired at present 75 years old. I can't do much any more plus it's harder and harder to see him from Arizona. I was told that he would always be provided for and that he would have everything he needed. I would like to have your views, as to his care. It's too late for me to have an extra monthly expense. I'm spending less, not more.

Ctrl: 72 Comment codes: 2 3

Other Comments: I have been real happy with ___'s progress since she has been in the Bellam house. I have seen a great improvement in her, and I'm very pleased with her care.

Ctrl: 74 Comment codes: 4 6 8

Other Comments: ___ has not been happy the time she has been in the community. My concern is medicare and medicaid cutbacks. These kids could very well end up on the street if funding is cut to providers.

Ctrl: 76 Comment codes: 2 3

Other Comments: I feel that since my son's move to community living, it has improved his personality and made him a person instead of a "client." He has been able to express his true feelings without feeling scared or worried, which every human being has a right [to do]. He has been able to enjoy his own interests as far as work and hobbies are concerned. He is developing and showing signs of happiness as an individual and is more at peace with himself (self-esteem). He is able to associate more with the public. He is becoming a well balanced young man. [Comment at #11: He has changed. He is more aware of his surroundings - what is home and what is school. He learned how to work for his money and he knows if he doesn't work he can't buy what he wants and needs, even though he still gets SSI.]

Ctrl: 82 Comment codes: 4

Other Comments: ___ was taken better care of at Ft. Stanton than any other place. He was dressed better, his clothes were better and they cleaned him all the time.

Ctrl: 85 Comment codes: 4

Other Comments: Work environment is definitely better. My son, working at Goodwill 5 days a week, is happier than he was with work at Los Lunas. Biggest complaint is constant staff changes and poorly trained staff. Also, Educare was cited for neglect when only one staff had to care for 3 severely physically handicapped clients for several weeks. A bad accident occurred as a result. Recreational services promised were swimming pool visits several times a week. Educare has NOT provided this— no pool visits for over a year. My son loved the pool at Los Lunas. His living environment has become more restrictive in the community. He used to roam the campus at Los Lunas; now he is restricted to his home.

Ctrl: 87 Comment codes: 2 3

Other Comments: When ___ resided at LL, there he would be with too many other residents that would fight and kick [him]. Because ___ could never talk it was hard for him to explain who or what was happening. One time he fell in the pool. Many accidents happened at [LL]. One time he was taken to Las Vegas. I had to hire a lawyer from legal [aid] and he brought him back. ___ was not insane; he is retarded and has no speech. Now he has learned very much. He gets along with the people he works [with]. There has not been a serious

will keep doing good in the community.

Ctrl: 89 Comment codes: 1 3

Other Comments: _ went to Los Lunas at age 19 -1959. When he did not improve they moved him to State Hospital, Las Vegas, NM. That was a very! very! bad nightmare for __ and for me. [Descriptions of two incidents at LV] Then he was moved next door to Meadows, which was better. The doors were not locked and he could go outside. But _ stayed inside, because he thought he should stay in.. He went to Ft. Stanton in 1982. FS was like heaven for _ after going through so much. I thought the community could not be better. However, I was wrong. Community is better, and my son ___ is happy and so am I.

Comment codes: 2 3
93 Ctrl:

Other Comments: I'm happy __ lives here in Las Vegas by me. Her house is not far from where I live. Most of all she is happy with her life now and she understands that I live close by. Also I pick her up on my days off and she can spend time with me. I am very happy she is close to me. We have a good relationship and also I'm very lucky she has wonderful staff workers and I'm luck in that way. PS Also since __ has been living here by me she has not been sick as she was sick a lot in the institution.

Ctrl: 100 Comment codes: 4 8

Other Comments: My brother, _____, was taken out of Los Lunas 2 years ago. Since then _____ has been going down. He is the hospital at t.h.c. Taking these people out of Los Lunas is a terrible mistake. I believe the best place for my brother is back in his home Los Lunas. ... **Comment codes: 4 8**

Ctrl: 106

Other Comments: As a whole the "forced" move of _____ out into the community has had a disastrous effect on the family. My father had a stroke and died, my mother had a major heart attack and required an angioplasty, my sister's health deteriorated and continues to do so. We as a family feel all of us including _____ would have been a lot healthier and happier had _____ been able to remain at Los Lunas. [Comments throughout questionnaire reflected different views toward 1st and current providers. Answers seem an amalgam, but specific problems may be moving toward resolution.] **Comment codes: 13 8**

Ctrl: 116

Other Comments: I believe my daughter is much happier living in the community. I think my only concern is my daughter's room mate was moved out due to her being "more advanced" and needed to move on. I guess this was a good thing for her. But on the other hand she wasn't being "held back" in the home she was in. I thought that living in the community meant all people living together. I didn't realize there had to be a separation between "advanced" and "not so advanced." My daughter and this girl were getting along so well!! **Comment**

Ctrl: 120 codes: 1 3

Other Comments: My ward is my daughter and she lives with me in he family home. I did not find assisted living or group homes to my satisfaction, therefore I have her living in the family home. I have adequate help; a caregiver 7 hrs a day, through Challenge N.Mex., and Respite through Pathways, Inc. Challenge provides 5 hrs daily of rehab. My ward has a very happy life with the family. I did not approve of the Jackson at first being one of the interveners. Now I think the Jackson suit was the best that every happened to my daughter.

Ctrl: 126 Comment codes: 8

Other Comments: It is a good idea to [move] handicapped people into their home community. But people are not too friendly in seeing someone with a handicap. People need to be educated about how they need to deal with [those] like our relatives. A lot of people, especially high class people, don't want anyone like our relatives near them or any of their business. As if they will die like they're 21 years old with no health problems or any one related to them will never be like our relatives. People are scared of our relatives and [this] hurts my feeling[s].

Ctrl: 129 Comment codes: 4 8

Other Comments: They moved her to boy's dormitory, which I thought it's crazy. __, she don't know what is going on around her, and a year ago they made her fall, which caused her to lose her teeth. They say she [?] her nice van. They just drive it around any way. Some parts are broke off and it is not [?] condition, on the van that they used to take to the doc, and class. Now they don't even feed her, her right arm is still the same. There is nothing change[d] in her, still the same. Cause, she not be care[d for?], that's all I've got to say for comment.

Ctrl: 150 Comment codes: 6

Other Comments: I feel that this move has put a lot of stress on me. When he was down at LL I didn't have to worry about Drs, Dentists, workers, whether his house had qualified help. Also if he had enough food in the house or if he had a good lunch to take to work. I didn't worry if he was safe. I'm checking in at his house everyday. I see him at work almost everyday which has been great for me. His work environment is wonderful but his home has a lot to be worked on.

DESCRIPTIVE STATISTICS
(shown in order of means, decreasing)

PERCEPTIONS OF CHANGES IN JACKSON CLASS MEMBERS' LIVES SINCE MOVING INTO THE COMMUNITY							
	Mean	Std. Dev.	Std. Error	Count	Minimum	Maximum	# missing
Living environment	4.040	1.185	0.097	149	1.000	5.000	4
Access to transportation	3.820	1.301	0.106	150	1.000	5.000	3
Opportunities for choice	3.810	1.173	0.098	142	1.000	5.000	11
Welfare and well-being	3.779	1.273	0.104	149	1.000	5.000	4
Social opportunities	3.669	1.318	0.109	145	1.000	5.000	8
Happiness	3.656	1.357	0.110	151	1.000	5.000	2
Medical quality	3.593	1.181	0.098	145	1.000	5.000	8
Health	3.534	1.216	0.101	146	1.000	5.000	7
Medical access	3.456	1.256	0.104	147	1.000	5.000	6
Access to recreation	3.453	1.449	0.119	148	1.000	5.000	5
Frequency of recreation	3.404	1.412	0.117	146	1.000	5.000	7
Access to therapies	3.397	1.330	0.112	141	1.000	5.000	12
PERCEPTIONS OF CHANGES IN THE FAMILIES' LIVES SINCE JACKSON CLASS MEMBER MOVED TO THE COMMUNITY							
	Mean	Std. Dev.	Std. Error	Count	Minimum	Maximum	# missing
Relationship with <i>Jackson Class</i> family member	3.858	1.082	0.089	148	1.000	5.000	5
Family relations	3.693	1.010	0.082	150	1.000	5.000	3
Your happiness	3.617	1.298	0.106	149	1.000	5.000	4
Quality of family life	3.517	1.002	0.083	147	1.000	5.000	6
Time with family	3.466	0.948	0.078	146	1.000	5.000	7
* Your spouse's job	3.441	0.938	0.097	93	1.000	5.000	60
* Your job	3.308	1.021	0.094	117	1.000	5.000	36
Own social life	3.279	1.090	0.090	147	1.000	5.000	6
Your recreation opport.	3.228	1.012	0.084	145	1.000	5.000	8
Your level of worry	3.135	1.501	0.123	148	1.000	5.000	5
Your expenses	3.126	1.033	0.089	135	1.000	5.000	18
* Not analyzed in final report.							